

The Person's Experience of End Stage Renal Disease and Haemodialysis Therapy

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ABSTRACT

This phenomenological study explores the person's experience of end stage renal disease (ESRD) and haemodialysis therapy. In-depth, qualitative interviews are conducted with sixteen participants on hospital-based haemodialysis therapy in Ireland. Using a hermeneutical approach to data analysis, the experience of waiting is formulated as an overarching pattern in the study. This pattern is constituted by three themes titled *Lost Time*, *Waiting for a Kidney Transplant*, and *Communicating with Nurses: Myth versus Reality*.

The participants indicate that they spend a substantial amount of time waiting when they attend haemodialysis therapy. The time spent waiting prevents them from engaging in everyday activities, and is interpreted as lost time. The theme *Lost Time* consists of two sub themes: (1) *Killing Time*, and (2) *Wasting Time*.

Because of the distressing experience of waiting, the participants look forward to receiving a kidney transplant. A successful kidney transplant offers the participants the possibility of freedom from the restrictions of the haemodialysis treatment regime. However, the shortage of donor organs means the waiting time for a transplant is excessive for many participants. The theme *Waiting for a Kidney Transplant* is composed of three sub themes: (1) *Living in Hope*, (2) *Uncertainty*, and (3) *Being on Hold*.

The lack of nurse-patient communication on the haemodialysis unit means the participants' experience of waiting is neither recognised nor addressed. Instead, the nurses seem to concentrate on the technical and physical aspects of patient care. The participants' descriptions of the superficial level of nurse-patient communication are discussed in the third and final theme in the study titled: *Communicating with Nurses: Myth versus Reality*. It is suggested that the technologically focused context of care on the haemodialysis unit may have contributed to the superficial levels of nurse-patient communication and interaction. Therefore, the need to move towards a model of supportive care using a continuous quality improvement (CQI) framework is recommended to enhance the quality of patient care.

CHAPTER 1 : INTRODUCTION TO THE STUDY

End stage renal disease (ESRD) is a chronic and life-threatening illness. It implies that the kidneys are permanently damaged and the person can no longer survive independently without renal replacement therapy. Renal replacement therapy involves either dialysis or a kidney transplant. The waiting process for a kidney transplant can take a substantial amount of time because there are a limited number of organs available. Therefore, while the person with ESRD waits for a kidney transplant, s/he must remain on dialysis therapy.

1.1 ESRD AS A HEALTHCARE ISSUE IN IRELAND

According to the unpublished National Renal Strategy Review (2006), 180,000 people in Ireland have some form of significant renal disease. Of these individuals, 3,000 are currently receiving renal replacement therapy. However, as the population ages, and the prevalence of diabetes rises, this number is expected to increase dramatically over the coming years. In particular, the review estimates that by the year 2011, the number of patients on haemodialysis therapy in Ireland will have doubled. It emphasises that renal transplantation in Ireland has not kept pace with the increasing number of dialysis patients. Hence, the development of a living-donor transplant programme is urgently needed in Ireland. While this expansion is being developed, the National Renal Strategy Review recommends an increase in haemodialysis stations to address the current overcrowding that exists on these units in Ireland.

These findings indicate that ESRD and dialysis therapy is a significant healthcare issue in Ireland, which will continue to intensify over the coming years. The spiralling demand for renal services and specifically for haemodialysis therapy may have profound implications on the person's experience of their illness and treatment. Therefore, it is an appropriate time for a study, which explores the illness experience of this patient group in Ireland.

1.2 OVERALL AIM OF THE STUDY

The overall aim of this study is to provide an accurate, detailed, and in-depth description of the person's experience of ESRD and haemodialysis therapy. The study is divided into six chapters. The following section presents an overview of each of these chapters.

1.3 SUMMARY OF THE CHAPTERS IN THE STUDY

Chapter two discusses the existing literature relating to the person's experience of ESRD and dialysis therapy. The findings indicate that the research in this area is predominantly based on an empirical psychological framework, which encapsulates a Cartesian dualistic world-view of the person. From this perspective, the person or self is understood as a cognitive or psychological "subject". Therefore, this research explores the person's experience of ESRD in terms of psychological concepts, theories, and ideas.

It primarily employs quantitative research designs to assess topics, such as depression, quality of life, and coping. Most of the studies employ questionnaires, which are structured and closed-ended. Thus, the important contextual and background features, which form the basis of the person's experience of ESRD, are not incorporated within this research.

There are a number of qualitative research studies, which offer some interesting contextual and background information on the person's experience of ESRD and dialysis. However, these studies are also predominantly grounded within a psychological framework. For instance, they adapt concepts, theories, and attributes, which are psychologically or cognitively based, to explore the person's experience of ESRD and dialysis. It is suggested that the Cartesian dualistic world-view of the person is also embedded within this research. In other words, these studies implicitly retain a cognitive perspective of the self as "subject".

This is not to suggest that there is anything inherently flawed with this research. Rather, it is proposed that by continuously interpreting the person from this psychological perspective, the existing research may have effectively concealed other equally significant interpretations of the person's experience of ESRD and dialysis. Therefore, based on the findings of the literature review, the need for an alternative approach to explore the person's experience of ESRD is recommended.

In particular, it is proposed that a hermeneutical phenomenological methodology, based on the philosophy of Martin Heidegger allows this alternative perspective to be provided. Heidegger's philosophy offers a way to overcome the primarily psychological interpretation of the person's experience that is contained in the existing literature. It facilitates a move away from the dualistic thinking of Descartes, and presents a radicalised approach to understanding the person, as being-in-the-world. Therefore, this study employs a hermeneutical phenomenological methodology to explore the person's experience of ESRD and haemodialysis therapy.

Chapter three presents a detailed account of the research methodology employed in the study. The chapter begins with an in-depth account of the philosophical perspective of the study. It provides a general overview of phenomenology, and then specifically focuses on the hermeneutical approach to phenomenology, presented by Heidegger (1962). In particular, Heidegger's notion of time or temporality is discussed in detail, since it provides the fundamental basis of his philosophical interpretation of the human being.

This philosophical perspective also provides the background to the research methods incorporated in the study. For instance, a purposive sampling strategy is used to select participants who provide a rich and in-depth description of their experience of ESRD and haemodialysis therapy. Data are collected using qualitative, in-depth interviews, which incorporate a conversational style. The data are analysed using a hermeneutical approach by Diekelmann, Allen & Tanner (1989), which is specifically formulated for use in Heideggerian hermeneutical studies.

Chapter four provides a discussion on the findings gleaned from the hermeneutical analysis of the interview data. The experience of waiting is presented as a constitutive or overarching pattern in the study. This pattern consists of three themes: *Lost Time*; *Waiting for a Kidney Transplant*, and *Communicating with Nurses: Myth versus Reality*.

The theme *Lost Time* refers to the participants' experience of waiting when they attend haemodialysis therapy. The excessive time spent waiting prevents the participants from engaging in normal everyday activities. Therefore, it is interpreted as time lost out of their everyday lives. The theme *Lost Time* is composed of two sub themes: *Killing Time* and *Wasting Time*.

The distress caused by the participants' experience of waiting means they look forward to receiving a kidney transplant. They believe a successful kidney transplant will free them from the restrictions of haemodialysis therapy. However, in order to receive a transplant, the participants have to wait until a suitable donor match becomes available.

The experience of *Waiting for a Kidney Transplant* is created as a theme in the study. This theme consists of three sub-themes: *Living in Hope*, *Uncertainty*, and *Being on Hold*. The participants describe their experience of living in hope, while they wait for a kidney transplant. The hope of receiving a transplant offers them the possibility of a normal life in the future. However, as the time spent waiting continues indefinitely, they become uncertain.

As a result of the experience of uncertainty, the participants are unable to contemplate possibilities for their futures. Moreover, the disruptions caused by the dialysis treatment regime limits their ability to participate in the lifestyle they took for granted in the past. Therefore, they convey their experience of being on hold, while they wait for a kidney transplant.

It is suggested that the participants' experience of waiting, illustrated in both themes, culminates in the existential moods of anxiety and boredom, advanced by Heidegger (1962, 1995). While the participants continue to endure the relentless experience of waiting, they attend the hospital for haemodialysis therapy three times each week. During this time, the nurses on the haemodialysis unit are the primary health care

provider for these patients. However, the participants' accounts emphasise that these nurses rarely communicate with them during their treatment. Instead, they confine their attention to the technical and physical aspects of care.

This superficial level of nurse-patient communication means the participants' experience of waiting is neither recognised nor addressed by the nurses. Moreover, the moods of anxiety and boredom that are embedded within their experience of waiting are also overlooked. The participants' experience of communicating with the nurses during haemodialysis is presented in the third and final theme in the study, labelled: *Communicating with Nurses: Myth versus Reality*.

Chapter five provides an overall discussion of the findings of the study. The existential moods of anxiety and boredom, depicted within the participants' accounts of waiting, are emphasised within the discussion. For instance, specific characteristics of these existential moods epitomise the concept of "enduring", advanced by Morse (2001). However, the psychological perspective of emotion retained within the concept of enduring is replaced with Heidegger's interpretation of mood, to make it more characteristic of the participants' experience of waiting. Therefore, in the second section of chapter five, a new "Model of Enduring" is proposed. This model combines specific features of Morse's concept of enduring, with Heidegger's existential account of mood.

According to Morse (2001), in order to recognise and respond to the experience of enduring, the nurse must take time to interact and communicate with the patient. However, as the participants' accounts reveal, the nurses on the haemodialysis unit spend very little time communicating with them during dialysis therapy. Instead, they concentrate almost entirely on the technical and physiological acts of care. The technologically focused context of care on the haemodialysis unit is discussed in the third and final section of this chapter.

Chapter six offers recommendations nursing and healthcare. In particular, it proposes the need to alter the current technologically focused context of care on the haemodialysis unit in order to provide supportive care for these patients. This chapter also provides the limitations and conclusion of the study.

CHAPTER 2 : LITERATURE REVIEW

This chapter reviews the literature concerning the person's experience of end stage renal disease (ESRD) and dialysis therapy. The aims of the review are threefold: (1) to conduct a hermeneutical analysis of the existing research literature related to the person's experience of ESRD and dialysis therapy; (2) to identify shortcomings in this research literature, and (3) to propose an alternative approach that may address the shortcomings identified in the literature.

2.1 INTRODUCTION & BACKGROUND

The existing literature signified that the onset of a chronic illness created many losses and disruptions in the person's life. For instance, Chesla (2005) indicated that chronic illness caused the person to lose confidence in their ability to function in work, social life, and family relationships. The losses experienced by these individuals represented a breakdown in their everyday life and was a fundamental source of suffering (Chesla, 2005). Correspondingly, a study by Bury (1982) also highlighted the losses associated with chronic illness, including the loss of bodily functions, the loss of an autonomous life, and the loss of relationships and roles. The study explored the subjective experience of chronic illness and described it as a disruptive event, where the structures of everyday life had disintegrated. Hence, the participants were required to re-structure their biography and self-concept in order to adapt to the illness.

Various authors claimed that the subjective experience of illness was influenced by the socio-cultural orientations of the individual and vice versa (Kleinmann, 1991; Frank, 1995; Toombs, 1995). This literature signified that the various ways individuals think, act, and behave in the lived world were shaped by these orientations. However, when faced with a chronic illness, the link between the self and his/her socio-cultural networks were challenged. Hence, the result was a breakdown of the person's everyday activities, roles, and relationships (Kleinmann, 1991; Frank, 1995; Toombs, 1995).

According to a study by Charmaz (1983), the lifestyle disruptions imposed by chronic illness were so profound that the participants suffered a loss of their self-image. The participants in the study had various chronic illnesses including renal disease, cardiovascular disease, diabetes, cancer, and multiple sclerosis. The participants indicated that the demands of the treatment regime of chronic illness resulted in a restricted life, where the illness was their primary focus. The restrictions in living culminated in a loss of activity, loss of employment, loss of financial status, loss of family relationships, and loss of social engagements for the participants. From the author's perspective, the participants watched their normal self-images prior to illness disintegrate without the replacement of equally valued new ones. This loss of the familiar self-image was a fundamental source of suffering for the participants in the study (Charmaz, 1983).

Similarly, Curtin et al (2002) stated that many of the lifestyle alterations caused by chronic illness were irreversible. Hence, the person was required to re-structure their self-identity to adapt to the changed life circumstances. However, the ability to adapt relied primarily on the severity of the illness and the accompanying treatment regime. According to Curtin et al (2002), the need for treatment with dialysis therapy provided ESRD with unique characteristics that made it particularly difficult for the individual.

2.2 END STAGE RENAL DISEASE

ESRD is a chronic and debilitating disease. In order to survive, the person must commence renal replacement therapy. There are three modalities of renal replacement therapy including kidney transplantation, haemodialysis therapy, and peritoneal dialysis therapy. A kidney transplant offers the person the possibility of regaining the lost renal function caused by ESRD. However, a suitable tissue match between the donor and recipient is required to ensure the success of a kidney transplant. Therefore, patients are placed on a transplant waiting list until a suitable donor match is located.

The waiting time for a kidney transplant can be excessive because there are a limited number of organs available. While the person waits for a kidney transplant, s/he must commence dialysis therapy. Moreover, kidney transplantation is not an option for

everyone. It may be contraindicated in individuals with additional co-morbid conditions, malignancy, or infectious complications. For these individuals, dialysis is the only treatment available for ESRD.

2.3 DIALYSIS THERAPY

There are two types of dialysis therapy: peritoneal dialysis and haemodialysis. Peritoneal dialysis is a treatment that uses the peritoneal membrane as a natural filter to remove toxic substances and fluid from the blood.¹ There are two main types of peritoneal dialysis: continuous ambulatory peritoneal dialysis (CAPD) and automated peritoneal dialysis (APD). CAPD is a manual procedure, which is performed independently by the person at home. It involves the instillation of a dialysis solution into the peritoneal cavity via a peritoneal catheter.² The dialysis solution is left to dwell in the peritoneum for about 4-6 hours, allowing dialysis to take place. The dialysis fluid is then drained away with the excess toxins and fluid from the person's blood. The person on CAPD repeats the same process up to four times a day.

APD requires a machine, which repeatedly inserts and drains the dialysis solution to and from the peritoneal cavity. This treatment is usually carried out at home while the person sleeps. Both forms of peritoneal dialysis require the person to be independent and self-caring with the management of their dialysis treatment regime.

During haemodialysis therapy, high volumes of the person's blood are continuously filtered through a dialyser (artificial kidney), where the blood is purified and returned to the patient via the venous blood system. The person undergoing haemodialysis therapy in the Republic of Ireland attends hospital three times per week for treatment sessions lasting approximately four hours.³ The need to regularly attend the hospital makes

¹ The peritoneum is a membrane lining the abdominal wall, the liver, stomach, and intestines. The peritoneal cavity, which exists within this membrane, can accommodate large volumes of fluid making it ideal for dialysis.

² A peritoneal catheter is surgically created through the person's abdomen to allow the instillation of the dialysis solution. A proportion of the catheter tubing lies outside the person's abdomen allowing for connection/disconnection of the dialysis solution to the catheter.

³ Unlike some other countries, the Republic of Ireland does not currently offer home haemodialysis therapy to individuals with ESRD. In the past, the waiting time for a transplant was so short that it was not deemed necessary to offer home haemodialysis therapy. However, in view of the longer waiting times for a transplant and the increasing patient numbers for dialysis, this might change in the future.

haemodialysis therapy a more restrictive treatment than peritoneal dialysis. Although these individuals are dependent on the dialysis machine and the nurses for their treatment, they are encouraged to be independent and live a normal life in between.

Access to the person's circulatory system is required during haemodialysis therapy. This allows the passage of the person's blood through the dialyser (artificial kidney) for purification. Arteriovenous fistulae (AVF) are the preferred mode of vascular access because they provide a more long-term form of access.⁴ However, it is not possible to create an AVF in all individuals. Hence, a prosthetic arteriovenous graft (AVG) may be considered for those who cannot have an AVF.⁵ In the event that both an AVF and AVG are contraindicated, then a central venous catheter is inserted to allow access to the patient's bloodstream for dialysis.⁶ A central venous dialysis catheter is a dual lumen catheter, which is inserted percutaneously into a central vein.⁷

It is important to reiterate that ESRD is a progressive and incurable disease. Dialysis and transplantation are merely treatments for the disease, but not cures. While the person waits for a kidney transplant, s/he has to continuously undergo dialysis therapy. Although kidney transplantation offers freedom from dialysis, it is not a permanent treatment. Kidney transplants do not last forever and the person eventually returns to dialysis therapy (Terrill, 2002). According to Kidney Research UK (2006), the survival rates for cadaveric kidney transplants is 85-90% at 1 year, 70% at 5 years, and 50% at 15 years, while the survival rates for live donor kidney transplants is 90-95% at 1 year, 80% at 5 years, and 60% at 15 years.

⁴ An AVF involves the surgical anastomosis (joining) of an artery to a vein. This allows arterial blood to flow through the vein, causing it to enlarge and expand. Once the fistula is given time to mature (about 6-8 weeks), two large bore needles can be inserted, allowing the person's blood to be circulated through the dialyser for purification during treatment.

⁵ A prosthetic AVG involves the implantation of a small piece of synthetic tubing (e.g. PTFE polytetrafluoroethylene or Dacron) between an artery and a vein. Once the graft is given time to heal (about 6 weeks), wide bore needles are inserted into the graft, allowing access to the person's circulation during haemodialysis therapy.

⁶ Contraindications include peripheral vascular disease, chronic and intradialytic hypotension, heart disease, morbid obesity, infections, skin problems, and hypercoagulable states.

⁷ The percutaneous insertion of a central venous catheter refers to the procedure where access to a central vein (subclavian, femoral, internal jugular) is performed via needle-puncture of the skin.

2.4 THE APPROACH OF THE LITERATURE REVIEW

The literature was reviewed intermittently throughout the full course of this study using electronic databases, such as Healthsource Nursing-Academic Edition, MEDLINE, CINAHL, Blackwell Synergy, SwetsWise, SpringerLink, PsychINFO, PsycARTICLES, Science Direct, BMJ Journals, SAGE journals, and Web of Science. A search of the literature was performed using the terms ‘experience’ AND ‘renal’ OR ‘kidney’ OR ‘dialysis’ OR ‘haemodialysis’ OR ‘hemodialysis’ OR ‘peritoneal dialysis’. Only articles in the English language were accessed. A search of the Cochrane Library’s Reviews of relevant areas was also conducted. In addition, manual searching of relevant textbooks, journals, and “grey literature” was performed. Key nursing PhD theses were studied, which specifically focused on various aspects of the person’s experience of living with ESRD, such as Sloan (1996) and Polaschek (2000).

The literature review was conducted using a hermeneutical analysis of studies related to the person’s experience of ESRD and dialysis. I was introduced to this approach at the Institute for Heideggerian Hermeneutical research, which I attended twice in the USA. This institute provided an advanced level of training for researchers using a Heideggerian Hermeneutical methodology to explore healthcare issues. Based on the knowledge I developed at this institute, I realised that a Heideggerian hermeneutical methodology does not merely apply to the research methodology section of a study. Instead, the interpretive nature of this approach forms the core of all stages of the research process, including the literature review. The hermeneutical analysis of the literature used in this study was based on an approach used by Scheckel (2005) in her Heideggerian hermeneutical study, which sought to understand the common practices used to reform nursing education.⁸

The studies were read in their entirety to obtain an overall understanding of the findings. Interpretive summaries of the relevant studies were written up with a list of the key findings. Using a process of reading, writing, and thinking about the findings in the literature, an extensive list of common themes were developed, which were used to describe the experiences of people with ESRD. These themes included the unpleasant

⁸ Martha Scheckel PhD, RN is Assistant Professor in Nursing at Viterbo University, Wisconsin, USA. I met Martha at the Institute for Heideggerian Hermeneutical research. She kindly e-mailed me her PhD thesis and shared her knowledge and skills on how to conduct a hermeneutic analysis of the literature.

physical symptoms of ESRD and dialysis, distressing emotional reactions and responses, loss, grief, suffering, restrictions of dialysis therapy, disruptions in lifestyle, the time consuming nature of dialysis, adjustment, transformation, coping, quality of life, embodiment, hope (specifically the hope of a transplant), self care, self-efficacy, autonomy, independence/dependence, the impact of technology, social support, and relationships with healthcare staff.

After conducting the interpretive analysis of the interview data and some initial discussion of the findings, I returned to the existing themes identified from the review of the literature. At this stage in the research, I had developed new perspectives and interpretations of the person's experience of ESRD and dialysis based on the data analysis stage. Hence, I brought this new interpretive lens to bear on the themes already identified within the literature. By using this interpretive approach, the literature review became more than a summing up of research findings. It involved a level of analysis, interpretation, and synthesis that offered novel interpretations of the findings from the studies related to the person's experience of ESRD. The primary objective of this interpretive process was to formulate constitutive or overarching patterns from the existing literature. These patterns constituted the research priorities that needed to be addressed in my study and included:

1. The predominantly psychological perspective, which was embedded within the existing literature related to the person's experience of ESRD.
2. The lack of contextual or background information about the person's experience of ESRD and dialysis, which existed in the quantitative literature on this topic.

These two constitutive patterns were emphasised throughout the literature review. They provided the overarching "interpretive" perspective or lens through which the literature was critiqued and presented.

The existing literature on the experience of ESRD predominantly evolved from a psychological perspective, which examined the person's experience of ESRD using a quantitative approach incorporating questionnaires. It is suggested that this research lacked important contextual information about the effects of the illness on the person's

life. Therefore, the literature review begins with a critical review of this literature, highlighting the potential limitations in its approach.

This discussion leads onto the review of the qualitative literature that pertained to the person's experience of ESRD and dialysis. Although there were a number of qualitative studies, which explored various aspects of the person's experience of ESRD, these studies were also based on a predominantly psychological framework. Hence, psychological concepts, theories, and emotions were often incorporated within these studies to describe the person's experience of ESRD.

The qualitative literature highlighted that the losses and lifestyle disruptions caused by a chronic illness, such as ESRD culminated in a loss of self. The loss of self was identified as a prominent source of suffering and initiated distressing emotional responses in the person, such as anxiety and uncertainty. Based on the findings of these studies, it seemed that people oscillated between the release and suppression of these distressing emotional responses. These features of the person's experience depicted certain characteristics of the model of suffering, formulated by Morse (2001). Hence, Morse's work on suffering was interwoven throughout the review of the qualitative literature to ensure an in-depth discussion of this literature was provided.

2.5 THE EXPERIENCE OF ESRD: A POSITIVISTIC PERSPECTIVE

The existing research related to the person's experience of ESRD and dialysis was predominantly based on an empirical psychological framework. This research used quantitative approaches to assess the person's subjective experience of quality of life, depression, coping, and adjustment, using questionnaires. It is proposed, that this psychological approach emanated from a positivistic paradigm, which failed to incorporate the significant contextual factors that constituted the person's experience of living with ESRD and dialysis therapy.

Positivism was a term used to describe an approach, which applied scientific methods to examine human experiences. It was a product of the Cartesian dualistic perspective of the human being, which existed at the time of its inception. Descartes was a

philosopher, natural scientist, and mathematician. According to his philosophy, the objects in nature had their properties identified in mathematical physics, such as shape, number, mass and motion (Hollis, 1994). Therefore, the material world consisted entirely of mathematical bodies (Fjelland & Gjengedal, 1994). Based on this philosophy, the human body, like any other body contained within the world, was also governed by the laws of mechanics (Hollis, 1994).

However, Descartes viewed the mind or soul as an immaterial substance, which was detached from the material world and subsequently not governed by natural laws (Hollis, 1994). He signified that we accrue all knowledge about the objects in the world through our five senses. From this perspective, consciousness was understood as a bubble or an enclosed cabinet; a circle of ideas and experiences where impressions occurred (Sokolowski, 2000). Our awareness was directed towards this circle of ideas and not directly toward the things outside. From this point of view, we were not in any direct contact with the objects in the world. Rather, we got to things only by reasoning from our mental or psychic impressions, which were contained in consciousness (Sokolowski, 2000). Thus, as Hollis (1994) pointed out, when we reported seeing a red rose, we were merely “reporting an effect on our consciousness brought about by a particular wavelength of light” (p29-30).

The philosophy of Descartes led to thinking in terms of two worlds: one “outer” world, which was independent of the perceiver, and one “inner” world, which consisted of mental or cognitive processes (Hollis, 1994). This notion of reason led to the modern divorce of mind and body, which was known as Cartesian dualism or the subject/object dichotomy. Positivism evolved from the Cartesian dualistic paradigm and was sometimes referred to as the philosophy of positive science. However, in modern thought, the term positivism is used to refer to a broadly empiricist approach to knowledge (Hollis, 1994). Positivists believed that this knowledge was obtained through a process of observation, induction, and experimentation known as empiricism.

Empiricism involved using the senses (in particular observation) to advance knowledge through a process of induction (Hollis, 1994). The approach prevented the contextual factors in the world of the individual from contaminating the empiricist’s ability to get at the “pure” subjective experience. By observing the subjective experience of the

object under study (i.e. the person), the empiricist was able to generate knowledge through inductive processes. The categories, which constituted this knowledge, were then tested deductively through the use of experiments (Hollis, 1994). These experiments served to validate the knowledge and develop theories.

According to Heidegger, all of the variations of modern psychology were held beneath this approach of the scientific method (Aho, 2007). This method reduced human behaviour to causal interactions and viewed emotional suffering from the perspective of detached objectivity. It is proposed that most of the research associated with the person's experience of ESRD and dialysis therapy emanated from an empirical psychological perspective. This was represented in the large body of research on depression, quality of life, coping, and adjustment, in relation to the person with ESRD. Some of these studies are discussed later.

Scott (2006) emphasised that patients presented to healthcare professionals with unique concerns about the potential impact of their illness on their everyday lives, their future, their families, and loved ones. These contextual factors formed the basis of their experience of illness and treatment. Therefore, it was imperative that healthcare professionals recognised and responded to these contextual factors, in order to provide care that was patient-centred and effective (Scott, 2006).

It is suggested that the existing psychological research largely overlooked these important contextual features, which constituted the person's experience of living with ESRD and dialysis therapy. This was emphasised in the research that assessed depression within this patient group. The majority of this research identified increased levels of depression in the person with ESRD. However, it is important to point out that many of the symptoms of ESRD are similar to depression. These include tiredness, sleep disturbance, loss of appetite, anorexia, weight loss, and loss of interest in sex. Therefore, it is suggested that without contextual information about the effect of the illness on the person's life, this research may be overestimating the levels of depression within this patient group.

The Beck Depression Inventory (BDI) (Beck et al., 1979) was a questionnaire commonly used to assess the level of depression in the person with ESRD. For instance, Elal & Krespi (1999) used the Beck Depression Inventory to assess depression in 200 haemodialysis patients in Turkey. The findings signified that 42% of the participants were clinically depressed, 33% were moderately depressed, and 25% were not depressed. According to the researchers, the population sample consisted mostly of unemployed individuals and this may have contributed to the high levels of depression reported in the study.

Watnick et al (2003) also used the Beck Depression Inventory to investigate the prevalence and treatment of depression among patients starting dialysis in the USA. The sample consisted of 123 patients with ESRD who had stated dialysis within ten days. The findings indicated that the prevalence of depression within the sample was 44%.

Similarly, McDade-Montez et al (2006) investigated the role of depression in withdrawal from haemodialysis in 240 patients with ESRD in the USA. The participants were followed for an average of four years after depression symptom assessment using the Beck Depression Inventory. The findings indicated that the high level of depression within the sample was a unique and significant predictive risk factor for the decision to withdraw from haemodialysis therapy.

Other researchers have also employed the Beck Depression Inventory to assess the level of depression in the person with ESRD (e.g. McGee et al., 1998; Wuerth et al., 2001; Davison & Jhangri, 2005; Kimmel & Peterson, 2006; Kalender et al., 2007). According to Beck et al. (1979), the inventory was based on a cognitive model of depression, which was developed from systematic clinical observations and experimental testing of patients with depression. The authors stated that by using this rigorous and scientific approach, they were able to determine broad categories, which constituted the subjective experience of depression. These categories made up the Beck Depression Inventory and included measurements of the person's perception of both the cognitive and somatic features of depression.

The cognitive features of depression contained on the questionnaire included feeling sad, feeling discouraged about the future, feeling worried, feeling guilty, feeling disappointed, having suicidal thoughts, and crying, while the somatic features included gastrointestinal disorders, loss of appetite, sleep disturbance, fatigue, aches and pain, and sexual dysfunction. Some, or all of these factors also appeared on other questionnaires that were commonly used to measure the subjective experience of depression in the person with ESRD e.g. the Hamilton Rating Scale for Depression (HRSD) (Hamilton, 1960).

For instance, Soykan et al (2004) sought to assess the frequency of psychiatric disorders in 50 patients with ESRD on haemodialysis therapy in Turkey. The findings highlighted that depression was the most common diagnosis occurring in 24% of the participants. Depression was assessed using the Hamilton Rating Scale for Depression. After six months, 14 participants were followed up and the level of depression remained unchanged.

A study by Wuerth, Finkelstein & Finkelstein (2005) aimed to identify and treat depression in patients maintained on peritoneal dialysis. The researchers screened 380 patients for depression using the Beck Depression Inventory. Forty-nine percent were deemed to have depression and were invited to pursue further assessment and treatment of their depression. Forty-five percent of the patients eligible for treatment agreed to further assessment and intervention. These patients were screened for depression using the Hamilton Rating Scale and eighty-four percent were identified as having major depression.

Similarly, Yucedal et al (2003) employed the Hamilton Rating Scale to assess the level of depression in dialysis patients in Turkey. The sample included 52 patients on haemodialysis and 26 patients on peritoneal dialysis. The findings indicated that the majority of patients in the haemodialysis group were diagnosed as having depression in various degrees. For instance, major depression was identified in 11 patients, moderate depression was identified in 10 patients, mild depression was identified in 21 patients, and no depression was identified in 10 patients. In contrast, fifty percent of the peritoneal dialysis group had depression. For example, major depression was identified in 2 patients, moderate depression was identified in 3 patients, mild depression was

identified in 8 patients, and no depression was identified in 13 patients. However, as the sample of patients on peritoneal dialysis was half the size of the haemodialysis patient group, it may be difficult to make accurate comparisons.

Yeh et al (2004) compared levels of depression in kidney transplant patients and chronic dialysis patients. Subjects included 102 patients on chronic dialysis (60 haemodialysis patients and 42 peritoneal dialysis patients) and 58 patients with a kidney transplant. Depression symptoms were assessed using the Hamilton Depression Rating Scale. The findings indicated that depression symptoms in the chronic haemodialysis patients were more severe than those of the kidney transplant group. This study primarily assessed adjustment in these patient groups. Therefore, a more detailed account of the study will be provided in the upcoming discussion on the literature related to adjustment.

As mentioned previously, the symptoms of ESRD are similar to the symptoms of depression. Therefore, many of the somatic features contained in the scales used to measure depression in the person with ESRD i.e. Beck Depression Inventory and Hamilton Rating Scale for Depression, were similar to the physiological symptoms of ESRD. This overlap illustrated a potential weakness in these scales to accurately measure depression in the person with ESRD. Moreover, it posed the question as to how researchers using these scales ascertained whether the somatic symptoms selected by the participants were actually related to depression, or merely a physiological symptom of their illness.

Indeed, Kimmel & Peterson (2006) acknowledged this overlap between the somatic features of depression and the physiological symptoms of ESRD, as a limitation of depression scales. The researchers addressed this problem by separating the somatic from the cognitive features of depression in the Beck Depression Inventory (BDI). By doing this, they were able to assess the cognitive features of depression in isolation of the somatic features. Consequently, they were able to limit the confounding influence of the symptoms of ESRD on their objective measure of depression.

The notion that the person's subjective experience of the somatic and cognitive features of depression could be separated, and assessed in isolation, epitomised the positivistic paradigm embedded within the psychological framework. To appropriately assess whether the somatic symptoms experienced by the person evolved from either ESRD or depression, additional contextual and background information from the patient was required. However, the collection of contextual information was not appropriate with the BDI, or indeed with many other psychologically based questionnaires used to measure the subjective experience of ESRD. Therefore, depression was repeatedly described as the most common psychiatric disorder within this patient group (Wuerth et al., 2001; Soykan et al., 2004; Wuerth, Finkelstein & Finkelstein, 2005; Kimmel & Peterson, 2006).

Darbyshire, Oster & Henning (2006) emphasised how the positivistic approach of psychology created a fragmented perspective of the patient's experience of illness. As a result, the constitutive parts of the person's experience were observed in isolation from the "supposedly contaminating influence of contextual features" (p755). The authors continued to suggest that this positivistic approach valued objectivity, measurement, and quantification. Therefore, the use of standardised tools to measure the psychological and social functioning of the individual was deemed most appropriate. However, the ability of the person to provide contextual data about his/her level of functioning in everyday life was limited by the closed-ended structure of these questionnaires.

Rose (1998) claimed that psychology should be understood as a technology. From the author's perspective, technologies consisted of an accumulation of knowledge, instruments, and systems of judgement, which had certain presuppositions and objectives about human beings. The technologies that Rose referred to were concerned with Foucault's view of governmentality. According to Foucault, technologies were invented for the regulation of conduct and the exercise of power over others (Irving, 2001). Hence, from Rose's (1998) perspective, psychology was a technology because it took the experience of the human being as its object. It ordered the experience, segmented it, and created relationships between elements, to convince us that existence was amenable to be viewed in terms of psychological truths (Rose, 1998).

The segmentation of the person's experience presented by Rose was conveyed in the research that pertained to health related quality of life (HRQL) in the person with ESRD. This research generally classified and segmented the person's quality of life into specific domains and categories. These categories/domains consisted of the individual's perceptions of his/her physical, psychological, and social wellbeing. For instance, Lamping (2004) pointed out that HRQL referred to a person's subjective perceptions of his/her illness and treatment and specifically "includes the impact of health on well-being in the core areas of physical and mental health, social and role functioning, and general health perceptions" (p63).

The Short-Form-36 (SF-36) (Ware & Gandek, 1998) was a widely used measure of HRQL in the research related to the person with ESRD. This 36-item generic measurement assesses health related quality of life by focusing on eight dimensions. These dimensions are the most frequently measured in health surveys and most affected by disease and treatment. There are 36 items addressed in the questionnaire. Thirty-five of the 36 items are reduced into eight scales representing physical functioning, social functioning, role functioning-physical, role functioning-emotional, mental health, vitality, bodily pain, and general health perceptions. The one remaining question is used to estimate the change in health status over time and is not counted in the eight items.

The questionnaire also addresses whether limitations in these areas are because of physical or mental health issues. Therefore, the eight scales of the questionnaire are further summarised into two summary scores: Physical Component Summary (PCS) and Mental Component Summary (MCS). The PCS measure is primarily comprised of the physical functioning, role functioning, physical and bodily pain scales. The MCS is primarily comprised of the mental health, role functioning, and emotional and social functioning scales.

Another measure specifically developed to assess HRQL in individuals with ESRD was the Kidney Disease Quality of Life Questionnaire (KDQOL) (Hays et al., 1994). This questionnaire consisted of the SF-36 as its generic core, and was supplemented with measures of specific concerns related to ESRD and dialysis. These included disease-specific items, such as symptom problems, effects of kidney disease on daily life, burden of kidney disease, cognitive function, work status, sexual function, quality of

social interaction, sleep, social support, dialysis staff encouragement, and patient satisfaction.

As discussed previously, the SF-36 consisted of both a mental health component (MCS) and a physical health component (PCS). According to Lamping (2004), it was important for HRQL measures to include both physical and mental components to allow the differences between both to be evaluated. However, the belief that the physical and mental health components of the person could be split up and observed in isolation, was indicative of the psychological segmentation of the person's experience, described by Rose (1998).

According to Rose (1998), the notion of psychology as a technology, was further reinforced by the technical means used by the discipline to get to its psychological truths. Rose described these techniques, as the techniques of positivism and included statistics and the experiment. By incorporating statistical norms and values, psychology was able to establish its scientific base, and enhanced its credibility with the physical sciences (Rose, 1998; Darbyshire, Oster & Henning, 2006). The use of an experimental approach evolved out of a desire for data, which could be quantified, generalised, and was suitable for comparison.

Indeed, this desire for quantitative data, which could be generalised and compared was reiterated in the literature on HRQL in the person with ESRD (Lamping, 2004). For instance, various studies compared the quality of life of patients with ESRD with samples of the general population. Cleary & Drennan (2005) employed a descriptive, cross-sectional, survey design to examine the quality of life of patients undergoing haemodialysis therapy at a hospital in the Republic of Ireland. Health related quality of life was assessed in a non-probability sample of 97 patients using the SF-36 questionnaire. The participants in the study reported significantly lower (worse) scores in seven of the eight scales of the SF-36 when compared with the general population.

The results of this Irish study were also comparable with other studies. For example, Timmers et al (2008) explored the associations between quality of life and illness perceptions in ESRD patients in the Netherlands. Quality of life was assessed in both haemodialysis patients ($n=91$) and peritoneal dialysis patients ($n=42$) using the SF-36.

The findings indicated that the quality of life of dialysis patients in the study was dramatically lower than the general population, especially for the physical aspects of functioning.

Shimoyama et al (2003) also examined health-related quality of life among peritoneal dialysis patients and their family caregivers in Japan. There were 26 peritoneal dialysis patients recruited in the study and quality of life was measured using the Kidney Disease Quality of Life Short Form questionnaire (KDQOL-SF). The findings indicated that patients scored lower than a normative population in all dimensions of the quality of life scale. However, the ability to generalise the findings may be limited by the small sample of patients in the study. Correspondingly, the findings of a study by DeOreo (1997) indicated that HRQOL was significantly lower in a sample of haemodialysis patients than a sample of the general population. The researchers used the SF-36 to assess the health status of 1000 patients on haemodialysis therapy in the USA.

The findings of this research related to HRQOL certainly provided evidence that quality of life was lower in patients with ESRD than the general population. However, in the absence of contextual information about the person's experience, it was difficult to ascertain the reasons why these deficits in quality of life existed and the potential implications they had on the person's life. These findings illustrated a need to conduct a qualitative enquiry that specifically focused on the person's experience of ESRD in an effort to contribute some of this essential contextual data.

Furthermore, the existing research repeatedly emphasised the need to assess quality of life in the patient with ESRD in an effort to target healthcare interventions to enhance the quality of life of this patient population (Timmers et al., 2008; Cleary & Drennan, 2005; Loos et al., 2003). However, the research related to the quality of life of the patient with ESRD was replete with contradictions and disparities concerning the level of quality of life within this patient group. There appeared to be little consensus as to what factors enhanced or diminished the person's quality of life. Consequently, for practitioners providing care to people with ESRD, these disparities made it difficult to relate the findings to their everyday care of these patients.

For instance, there seemed to be little consensus about the relationship between dialysis adequacy and quality of life. The study by Cleary & Drennan (2005) sought to identify if there were any differences in quality of life between people who were adequately dialysed and those inadequately dialysed. Dialysis adequacy was assessed using urea kinetic modelling (Kt/V). The findings suggested that no significant differences were found between the well- and less well-dialysed groups on the majority of quality of life outcome variables. Morsch, Gonçalves & Barros (2006) subscribed to this perspective in a study, which investigated the health related quality of life of 40 haemodialysis patients in Brazil. A descriptive cohort study design was employed and quality of life was assessed using the SF-36 questionnaire. The findings did not reveal a correlation between dialysis adequacy (Kt/V) and HRQOL.

In contrast, some studies highlighted that better dialysed patients reported better quality of life than patients who were inadequately dialysed (Chen et al., 2000; DeOreo, 1997). For instance, the study by Chen et al (2000) used the SF-36 questionnaire to examine the quality of life of 67 long-term peritoneal dialysis patients in China. The results of the study suggested that the quality of life of the participants was closely related to dialysis adequacy, as determined by Kt/V . Similarly, the study by DeOreo (1997) found that patients who were receiving adequate dialysis, as measured by Kt/V levels reported better quality of life than less well-dialysed patients.

There also seemed to be uncertainty as to whether the length of time on dialysis affected quality of life. For example, Bakewell, Higgins & Edmunds (2002) sought to determine the key factors that affected quality of life in peritoneal dialysis patients. They reviewed the results of a longitudinal study, which examined the quality of life of 88 patients on peritoneal dialysis therapy. Quality of life was assessed at enrolment to the study and at six-month intervals during the two-year study period. The sample consisted of patients from Indo-Asian and white European backgrounds and quality of life was assessed using the Kidney Disease and Quality of Life Short Form questionnaire (KDQOL-SF). The findings indicated that quality of life declined steadily for the participants throughout the duration of the study.

Contrary to these findings, the participants in the study by Morsch, Gonçalves & Barros (2006) who had been undergoing haemodialysis therapy for more than one year had better HRQOL results than patients who had been on the treatment for less time. These findings were corroborated in a cross sectional study by Neto et al (2000) which measured quality of life in 80 patients on haemodialysis therapy in Brazil. All participants in the study were on haemodialysis for less than sixty days and the researchers used the SF-36 to measure their quality of life. The findings indicated that the quality of life of the participants in the study was impaired in these early stages of dialysis treatment.

It seemed that there was little consensus as to what factors enhanced or diminished quality of life, which made it difficult to see how these findings could be applied in the renal healthcare setting. However, as suggested by Lamping (2004), the primary focus of measurements of HRQL was more specifically to provide evidence on the effectiveness of new treatments. The author emphasised that these evaluations of quality of life allowed the financial costs of treatment to be weighed against the benefits to the patient. Hence, it seemed that cost-effectiveness was at the core of the HRQL research. Indeed, embedded in the discussion by Lamping was the need for reliable, valid, and responsive tools to measure HRQL, in an effort to provide robust methods to decide who received expensive treatments (e.g. dialysis) in the future.

The author referred to a study by Mc Kenzie et al (1998), which signified that HRQL was a prominent reason why nephrologists in the UK and Canada decided whether or not to provide dialysis therapy. She insisted that these findings conveyed the significance and relevance of HRQL measures in the effective provision of treatment. However, it could also be argued that these findings add weight to the earlier argument by Rose (1998), which signified that psychology was a technology, i.e. something that was invented for the regulation of conduct and the exercise of power over others. From Rose's perspective, the technology of psychology led us to believe that the person's existence (including the quality of that existence) could be calculated and evaluated in terms of psychological truths. This was clearly indicated in the study above by McKenzie et al (1998), where 'objective' psychological measures were deemed to influence the person's access to the life-saving treatment of dialysis.

Based on the findings of the literature thus far, it is suggested there is a need for contextual information based on the person's perspective of ESRD to supplement the current measures of quality of life. Without this important information, we are failing to develop a comprehensive, in-depth understanding of the experience of ESRD for these individuals.

This lack of contextual information was also a significant shortcoming in the existing research on coping with ESRD. This research was predominantly based on the theoretical framework of coping, advanced by Lazarus & Folkman (1984). The framework highlighted a distinction between "problem solving" and "emotion-focused" coping. According to the authors, emotion-focused coping referred to the cognitive processes used to lessen emotional distress e.g. avoidance, distancing, hope, and optimism. In contrast, problem-solving coping referred to the cognitive processes that were aimed at solving a problem e.g. generating alternative solutions, weighing alternatives, and choosing among them. The cognitive processes of coping (i.e. problem-solving or emotion-focused) determined how the person behaved in response to stress.

A descriptive correlation study by Cormier-Daigle & Stewart (1997) explored the coping strategies of 30 men on haemodialysis therapy in Canada. The Ways of Coping questionnaire was used to assess the coping strategies of the men in the study. This questionnaire was developed by Lazarus & Folkman (1984) and based on their theoretical framework of coping. The participants in the study used both problem-focused and emotion-focused forms of coping. However, problem-focused coping was the most predominant coping strategy employed. The participants tended to rely on emotion-focused types of coping, such as avoidance as a way to handle the illness-related complications. The authors deduced that the participants chose to avoid thinking about these complications because they potentially realised they had little control over their outcome. However, the small convenience sample and the sole inclusion of men, prohibits the generalisability of the results.

Previous studies have also shown that patients on dialysis use problem-focused coping methods to a greater degree than emotion-focused ones. For instance, Mok & Tam (2001) examined the coping methods of 50 patients from three chronic haemodialysis centres in Hong Kong. According to the researchers, the participants in the study used more problem-orientated coping methods than emotion-focused coping methods. Over half of the participants in the study had been on haemodialysis therapy for more five years. The researchers suggested that the lengthy time spent on dialysis might have enabled the participants to accept the reality of living with the illness. Mok & Tam (2001) assessed coping using the Jalowiec Coping Scale (JCS) (Jalowiec, Murphy & Powers, 1984). The small, convenience sampling strategy employed in the study meant the findings could not be generalised to the larger population of patients with ESRD.

The Jalowiec Coping Scale (JCS) was a predominant tool used in other studies to assess coping in patients with ESRD. The scale was also based on the theoretical framework of coping advanced by Lazarus & Folkman (1984). Jalowiec grouped the problem and emotion focused coping strategies identified by Lazarus & Folkman (1984) into eight coping styles: Confrontative; Evasive; Optimistic; Fatalistic; Emotive; Palliative; Supportant; and Self-reliant. The optimistic coping style was identified as a predominant coping style amongst patients with ESRD.

For example, a descriptive-correlational study by Logan, Pelletier-Hibbert & Hodgins (2006) examined the coping strategies used by hospital-based haemodialysis patients. The Jalowiec Coping Scale was used to assess the coping strategies reported in a convenience sample of 50 patients aged sixty-five and over. The sample was recruited from two sites in Canada. The most frequently used coping style was the optimistic style. The participants described this optimistic style as ‘keeping a sense of humour’, ‘looking at the good side’ and ‘thinking positively’.

Lindqvist, Carlsson & Sjoden (2004) used the Jalowiec Coping Scale to examine the coping strategies of 30 people with kidney transplants in two hospitals in Sweden. The findings indicated that the participants most frequently used optimistic, supportive, and self-reliant coping styles. The emotive and evasive coping styles were used least by the participants and were regarded as the least effective styles. The small, non-random

sample meant the findings were not representative of the accessible population of kidney transplant patients.

Similar findings were reported in a study by Lindqvist & Sjoden (1998), which explored coping strategies among patients on continuous ambulatory peritoneal dialysis. The Jalowiec Coping Scale was used to assess coping in 26 patients selected from three hospitals in Sweden. The optimistic coping style was the most frequently used by participants in the sample and was regarded as the most effective. The participants also used self-reliant, confrontative, fatalistic, and supportant coping styles. The emotive and evasive coping styles were the least frequently used by the participants. The participants who reported using these styles rated themselves as less effective in managing their illness and treatment. The small sample size made it impossible to generalise the findings of the study to the wider population of dialysis patients.

According to Polit & Hungler (1999), the use of an appropriate sample size and sampling plan allowed the researcher to be reasonably confident that the sample was representative of the target population. Therefore, the authors recommended the use of large, probability samples as the only viable way of obtaining representative samples in quantitative studies. They continued to suggest that the use of non-probability sampling strategies was problematic in quantitative research studies because these samples were rarely representative of the researcher's target population. As highlighted in the studies outlined above, the use of small, non-probability sampling strategies made it impossible to generalise the findings to the larger population of patients with ESRD. Polit & Hungler (1999) indicated that if the researcher had no alternative except to use a convenience sample, a simple way to increase the generalisability of quantitative studies was to select participants from two or more sites. While the researchers within these studies did recruit participants from two or more sites, the small number of patients selected from each site offered little to enhance the generalisability of the findings.

It is also important to point out that the coping scales employed to assess coping in the person with ESRD (e.g. Jalowiec Coping Scale and Ways of Coping questionnaire) used a checklist approach, whereby the person ticked off the coping strategies they primarily used. However, Lazarus & Folkman (1984) emphasised that coping styles were not static but dynamic and rapidly changing. Both coping styles facilitated and

impeded each other in the coping process.. For example, a student may be highly anxious prior to an exam (emotion-focused coping) but this anxiety decreased when s/he turned to the task (problem-focused coping) of actually working through the paper (p153).

These dynamic characteristics of coping questioned whether it was appropriate, or even possible to assess the person's coping processes using a checklist approach. Darbyshire, Oster & Henning (2006) raised this point in relation to the use of coping scales to examine the adaptation of children with chronic renal disease. Drawing on the work of Danoff-Burg, Ayala & Revenson (2000), the authors emphasised that using a checklist approach to assess coping, provided an oversimplified description of the coping process. By excluding the contextual features of the person's experience, a checklist approach effectively overlooked the complexity of coping (Darbyshire, Oster & Henning, 2006). Therefore, in order to pick up on the rapidly changing features of the coping process, there was need for qualitative, contextual data on the person's experience (Darbyshire, Oster & Henning, 2006). To re-iterate, this contextual data included the person's unique concerns about the impact of the illness on his/her everyday life, future, and meaningful relationships with family and loved ones (Scott, 2006). Without this essential contextual information, it was not possible to appropriately assess the coping skills of the person with ESRD.

The lack of background and contextual information on the person's experience may also result in the person with ESRD being incorrectly labelled as maladjusted or maladapted. For instance, the existing psychological research used scales, such as the Psychosocial Adjustment to Illness Scale-Self Report (PAIS-SR) (Derogatis, 1986) to measure adjustment in patients with ESRD (Kaplan De-Nour, 1982; Kimmel et al., 1995; Courts & Boyette, 1998; Tanyi & Werner, 2003, Yeh et al., 2004). The PAIS-SR was designed to assess adjustment in groups with chronic illnesses. It consists of forty-six items categorised into seven domains. These domains include health care orientation, vocational environment, domestic environment, sexual relationships, extended family relationships, social environment, and psychological distress.

Tanyi & Werner (2003) used the PAIS-SR to assess the adjustment of 65 women receiving haemodialysis in the USA. The findings indicated that the majority of women were fairly well adjusted to their illness and treatment. The researchers suggested that this finding may have occurred because nearly half of the sample were sixty years or over. It may be that with advancing age, the women's expectations of their health were lower. Furthermore, better adjustment of these women may have also related to time since diagnosis. Many of the women had several years of experience with their illness, which may have allowed them time to reach adjustment (Tanyi & Werner, 2003).

The women in the study did report lower adjustment in the vocational domain, social environment domain, and the sexual relationships domain of the PAIS-SR. The researchers suggested that the lower adjustment in the vocational domain was possibly due to the fact that the majority of women (87.7%) in the sample were not working. They signified that the lower scores in the social environment domain could possibly have occurred because haemodialysis took up too much time and resulted in too much fatigue for the women to be fully engaged in regular social activities. Adjustment problems in sexual relationships may be due to feelings of sexual unattractiveness or due to altered body image (Tanyi & Werner, 2003).

The convenience sample combined with the sole inclusion of women limited the generalisability of the findings of this study. Moreover, forty-seven participants completed questionnaires independently, whereas 18 requested questionnaires to be read to them because of poor eyesight or having their dominant arm used for dialysis. This may have influenced the responses of these participants.

Courts & Boyette (1998) used a comparative descriptive study to explore the psychological adjustment of male patients on three types of dialysis. These treatment modalities included peritoneal dialysis, home haemodialysis, and hospital based haemodialysis therapy. The PAIS-SR was used to measure adjustment in 15 participants, with five in each dialysis group. The findings indicated that the patients on home haemodialysis had the highest level of psychosocial adjustment to illness. The participants on home haemodialysis and peritoneal dialysis had higher levels of psychosocial adjustment to illness than patients on hospital based haemodialysis. Therefore, the patients on hospital-based haemodialysis had the lowest levels of

psychosocial adjustment to illness. The small, convenience sample and the sole inclusion of males prohibited the researcher's ability to generalise the findings.

Yeh et al (2004) sought to compare psychosocial adjustment to illness in patients with generalised anxiety disorder and patients with end-stage renal disease. Subjects included 102 patients on chronic dialysis (60 haemodialysis patients and 42 peritoneal dialysis patients), 58 patients with a kidney transplant, and 42 patients with general anxiety disorder. The evaluations included the PAIS-SR, the Hamilton Depression Rating Scale, and the Hamilton Anxiety Rating Scale.

The patients with general anxiety disorder were assessed using these questionnaires before commencing five weeks of anxiolytic treatment and were re-assessed after the treatment. The chronic dialysis patients and the kidney transplant patients received only one assessment using the questionnaires. The researchers indicated that patients with general anxiety disorder are deemed physically healthier than patients with ESRD. However, psychosocial adjustment to illness of the patients with general anxiety disorder was not superior to that of patients in the chronic dialysis and kidney transplant groups. The researchers also indicated that adjustment was better in the kidney transplant group than in the chronic dialysis group, while adjustment was better in the haemodialysis patients than in the peritoneal dialysis patients.

There were various limitations in this study, which meant the findings had to be assessed with caution. The chronic dialysis patients and the kidney transplant patients were only assessed once with the questionnaires, while the patients with general anxiety disorder received two assessments. The researchers indicated that the primary aim of the study was to compare adjustment to illness in patients with generalised anxiety disorder and patients with ESRD. However, they proceeded to provide an intervention for the patients with generalised anxiety disorder (five-week anxiolytic treatment) and did not provide any intervention for the chronic dialysis group or the kidney transplant group.

To accurately measure the effect of the anxiolytic treatment for patients with general anxiety disorder, it was necessary to compare this group with a similar group of patients. It was impossible to compare the effects of an intervention in patients with generalised anxiety without the use of a control group with matching characteristics. It seemed that the researchers used the group of patients with ESRD i.e. chronic dialysis and kidney transplant patients, as the control group in the study, as they provided no intervention for these patients. However, the use of a group of patients with ESRD made it difficult for the researchers either to match the groups or to control for extraneous variables. In order to assess the impact of the intervention, the researchers needed to have matched groups of patients and needed to control for extraneous characteristics. The use of a non-probability sampling strategy to recruit patients also limited the generalisability of the findings. These weaknesses prohibited accurate comparisons to be drawn within the study.

In a study to measure aspects of quality of life in haemodialysis patients, Kimmel et al (1995) used the PAIS-SR to assess psychological adjustment to illness in 149 patients recruited from three sites in the USA. The researchers also used a range of other questionnaires to measure depression (Beck Depression Inventory), social support (The Multidimensional Scale of Perceived Social Support) functional ability (Karnofsky Score) and disease severity (Severity Coefficient). The objective of the study was to assess the relationship between these measures. The findings indicated that psychosocial adjustment to illness correlated with various parameters of social, physical functioning, and wellbeing within the participants. However, it is important to point out that the researchers only assessed three of the six domains of adjustment from the PAIS-SR i.e. Vocational, Relationship-Sexual, and Social Environment. Therefore, this narrow assessment of adjustment limited the conclusions that could be drawn from the findings. In addition, ninety-three percent of patients enrolled in the study were African-American, which meant the findings could not be generalised to patients with more diverse backgrounds.

The researchers using the PAIS-SR scale calculated a score, which represented the person's psychosocial adjustment to illness. Higher levels of psychosocial adjustment to illness were illustrated with lower PAIS-SR scores. Therefore, individuals who failed to achieve a score, which was indicative of a specific degree of normality in the seven

domains, were reported as being maladjusted. However, the qualitative literature, which will be discussed later, signified that some people who described themselves as being well adjusted, struggled on a daily basis to integrate the effects of their illness and treatment into their lives (Polaschek, 2000; Curtin et al., 2002). This relentless battle to participate in life while on dialysis was part of the successful adjustment to the illness and treatment. While many individuals considered themselves to be well adjusted, they might not appear that way when assessed using psychological adjustment scales.

Darbyshire, Oster & Henning (2006) claimed that the mismatch between the person's experience of adjustment to illness and the psychological interpretation of this experience, lay in the definition of normality. Normality from the perspective of psychology was usually based on the psychosocial functioning of a group of normal healthy subjects. However, this was not necessarily normality for the person with ESRD on dialysis. As Curtin et al (2002) pointed out, the person with ESRD on dialysis had to establish a "new" normal. However, in the absence of more qualitative contextual data about the person's experience of ESRD, it was not possible to establish what this new normal meant. Hence, there was a risk of patients who were potentially well adjusted being viewed incorrectly as maladjusted.

To summarise, the existing research predominantly explored the person's experience of ESRD and dialysis from a psychological perspective using quantitative methodologies. This research used questionnaires, which focused on the person's subjective experience of illness. The influence of the positivistic paradigm on this research meant that important contextual information about the person's experience of living with ESRD and dialysis was not addressed. Consequently, this research failed to provide a comprehensive understanding of the person's experience of living day-to-day with ESRD and dialysis therapy. In the following section, the experience of ESRD presented in the qualitative literature, will be discussed in detail.

2.6 THE EXPERIENCE OF ESRD: THE QUALITATIVE PERSPECTIVE

There were a growing number of qualitative research studies, which explored various aspects of the person's experience of ESRD. This research offered valuable and interesting insights into the person's perceptions and experience of his/her illness and treatment. However, the majority of qualitative studies were also primarily grounded within a psychological framework, which drew on psychological concepts and theories to explore the person's subjective experience of ESRD and dialysis. Hence, this research also represented a Cartesian dualistic world-view of the person.

Indeed, Leonard (1994) emphasised that nurses were preoccupied with adapting the Cartesian doctrine in their studies of the person's experience of illness. As a result, these studies provided a perspective of the self as subject, "an uninvolved self passively contemplating the external world of things via representations that are held in the mind" (p44). From this perspective, the self (person) was always understood as "subject" and the world or environment as "object". The subject understood and experienced the world through the ideas, beliefs, and values that were cognitively developed and retained in the mind (Leonard, 1994).

Because of this Cartesian view of the self, nursing research tended to explore the person's experience of illness in terms of cognitive variables such as traits, attributes, values, and emotions. However, it is suggested that by consistently limiting qualitative research to the concepts and theories of psychology, additional important insights into the person's experience of ESRD may remain concealed.

The discussion that follows provides an analysis of the existing qualitative literature associated with the person's experience of ESRD and dialysis therapy. Much of this research adapted the ideas, concepts, and theoretical frameworks from the broader body of qualitative literature related to the person's experience of chronic illness. Therefore, this literature will be interwoven throughout the review to ensure a comprehensive understanding of the person's experience of ESRD is gleaned.

The existing qualitative literature described “suffering” as a significant feature within the person’s subjective experience of chronic illness (Charmaz, 1983; Kleinmann, 1991; Morse & Penrod, 1999; Polaschek, 2000; Hagren et al., 2001; Morse, 2001; Ohman, Soderberg & Lundman, 2003; Chesla, 2005; Hutchinson, 2005). There were various factors associated with the experience of suffering, which were subsequently highlighted in the literature related to the person’s experience of ESRD on dialysis.

For instance, the unpleasant physical symptoms of chronic illness were repeatedly cited as prominent characteristics of suffering (Cassell, 1991; Kleinmann, 1991; Frank, 1995; Charmaz, 1999; Ohman, Soderberg & Lundman, 2003; Mc Cabe, 2004). Similarly, the existing qualitative literature on the person’s experience of ESRD, also found the physiological symptoms to be source of intense distress and suffering for the person (Gregory et al., 1998; Polaschek, 2000; Hagren et al., 2001; Heiwe, Clyne & Dahlgren, 2003; Germain & Mc Carthy, 2004; O’ Sullivan & Mc Carthy, 2007). Indeed, a study by Saini et al (2006) indicated that individuals with advanced renal disease had a symptom burden that was statistically indistinguishable from patients with cancer. Although the sample in the study was small ($n=22$), the findings suggested that the physical symptoms of renal disease were a significant burden for some people.

Brown, Chambers & Eggeling (2007) implied that the additional co-morbid conditions, which accompanied ESRD, made it the most symptomatic of any chronic disease group. Furthermore, there were a multitude of disease-specific complications, which resulted in severe and sometimes life-threatening consequences for the individual (Ballinger & Patchett, 2000; Ferro, Chambers & Davison, 2004; Brown, Chambers & Eggeling, 2007).⁹

Polaschek (2000) explored the experiences of renal illness for six men on home haemodialysis therapy in New Zealand. The critical interpretive methodology employed in the study was based on the work of Foucault. Data were collected using semi-structured interviews followed by critical interpretation of the interview text. The experience of suffering from the unpleasant physiological symptoms of ESRD was significant for the participants in the study. Polaschek (2000) indicated that the

⁹ See Appendix A (p307) for a list of the co-morbid, and disease-specific physiological complications associated with ESRD.

dominant discourse amongst healthcare personnel assumed that dialysis therapy effectively removed the distressing physical symptoms of ESRD. However, in contrast to the dominant discourse, the findings of the study implied that despite excellent clearance of fluid and toxins, the participants continued to suffer from these symptoms. Moreover, they had a significant impact on the participants' ability to function normally on a daily basis. The sole inclusion of men was a potential limitation of the study.

Similarly, a qualitative hermeneutical study by Nagle (1998) indicated that even vigilant adherence to the dialysis treatment regime did not relieve the physiological complications of ESRD for all individuals. The study explored the experience of technology for eleven patients with ESRD on hospital-based haemodialysis therapy in Canada. Open-ended interviews were conducted with six male and five female participants. An approach to data analysis by Diekelmann, Allen & Tanner (1989) was used to analyse the interview texts. This method of data analysis was appropriate for use in this study, as it was specifically developed for studies using a hermeneutical phenomenological methodology.

The findings implied that while most of the participants strictly adhered to the dialysis treatment regime, they continued to experience the distressing physical symptoms of ESRD. Because of these complications, the participants had begun to realise that the technology of dialysis minimised, but did not prevent further deterioration in their physical health. They described how over time the degenerative changes and declining stamina caused by the disease, placed limitations on their ability to perform everyday activities.

Although ESRD is a chronic, life-long illness, it also includes acute episodes, which contribute to its distinctiveness and complexity.¹⁰ The literature signified how the acute complications of dialysis decreased the efficiency of the treatment and resulted in prolonged hospitalisation for the person (Challinor, 1998; Turner, 1998; Kotanko & Levin, 2008). Repeated hospitalisation merely contributed to the lifestyle disruptions of the person with ESRD.

¹⁰ See Appendix B (p309) for a list of the acute complications of ESRD and haemodialysis therapy.

According to Morse (2001), the predominant role of medicine meant the experience of suffering was commonly linked to pain and other unpleasant physical symptoms. However, the author emphasised that the concept of suffering was more extensive than this narrow focus. Other authors subscribed to this perspective and signified that the losses and lifestyle disruptions incurred by chronic illness were a fundamental source of suffering for the individual (Charmaz, 1983; Kleinmann, 1991; Frank, 1995; Toombs, 1995; Morse, 2001).

2.6.1 THE LOSSES AND LIFESTYLE DISRUPTIONS OF ESRD & DIALYSIS

The existing literature highlighted many losses and lifestyle disruptions caused by ESRD and dialysis therapy. For instance, a Swedish study by Heiwe, Clyne & Dahlgren (2003) illustrated the loss of physical functioning experienced by sixteen patients on peritoneal dialysis and haemodialysis therapy. Phenomenography was the research methodology employed to understand the subjective experiences of the participants in the study. Phenomenography is an empirical, psychological approach to phenomenology, which focuses on the psychological or cognitive experiences of the person. The participants in the study reported how the persistent loss of energy caused by the fatigue of renal disease made them feel powerless and feeble. They described experiences of being exhausted and washed out. The fatigue contributed to a loss of functional capacity, which culminated in limitations in everyday activities such as walking, managing personal hygiene, preparing meals, and doing housework. For some participants, even the ability to stay awake for the whole day was a challenging endeavour.

Similar findings were reported in a study by Al-Arabi (2006), which sought to describe how eighty people on haemodialysis in the USA subjectively experienced their quality of life. The loss of energy and fatigue associated with ESRD hindered the participants' ability to perform normal activities, such as working, socialising, and travelling. The researcher used a constant comparative method of data analysis, which is predominantly associated with a grounded theory methodology. However, there was no information as to whether a specific methodological approach was used in the study.

According to Kimmel & Levy (2001), about two-thirds of ESRD patients on dialysis were unable to return to their employment. The physical complications of ESRD and dialysis meant returning to a strenuous job was too demanding for some patients (Kimmel & Levy, 2001). Various authors reported that the inability to work created financial difficulties for patients with ESRD (White & Grenyer, 1999; Sloan, 2002; Reiter & Chambers, 2004; Kaba et al., 2007).

The restrictive nature of the dialysis treatment regime created significant lifestyle disruptions for the individual (White & Grenyer, 1999; Caress, Luker & Owens, 2001; Curtin et al., 2002; Faber, de Castell & Bryson, 2003; Al-Arabi, 2006). The literature highlighted how individuals on dialysis were required to comply with regular dialysis therapy sessions, strict dietary and fluid restrictions, and the intake of multiple medications. The intrusiveness of the treatment regime impacted on their ability to perform normal everyday activities.

For example, Curtin et al (2002) explored the experience of eighteen long-term survivors on haemodialysis therapy in the USA. Semi-structured interviews were carried out with ten male and eight female participants. The interview data were analysed using qualitative content analysis. While the researchers signified that they used an exploratory-descriptive research approach, they did not seem to incorporate a specific research methodology. The findings indicated that the intrusiveness of haemodialysis therapy made ESRD a particularly difficult disease to manage. It required radical lifestyle modifications to accommodate the dialysis treatment regime.

The study by Al-Arabi (2006) also identified “living a restricted life” as a core theme in the participants’ experience of haemodialysis therapy. The participants described how the burdens and demands of ESRD and dialysis therapy had inflicted many losses on their lives. Among these were the loss of freedom, loss of choice, loss of physical appearance, and the loss of decision-making opportunities. The participants felt tied down due to the restrictive nature of the dialysis treatment regime. They felt their lives were entirely scheduled around dialysis therapy and were subsequently unable to perform normal everyday activities.

Correspondingly, participants in the study by Nagle (1998) highlighted how the restrictions and limitations of ESRD and haemodialysis therapy hindered their ability to engage in a normal life. The participants stated that their lives were almost engulfed by ESRD and dialysis therapy. Their life patterns were entirely structured around the self-management of their illness and treatment regime. In addition, the time-consuming nature of the treatment meant they had to repeatedly re-arrange and cancel everyday activities.

Various studies illustrated the time-consuming aspects of dialysis therapy (Polaschek, 2000; Hagren et al., 2001; Curtin et al., 2002; Faber, de Castell & Bryson, 2003; Heiwe, Clyne & Dahlgren, 2003; Hagren et al., 2005; Walton, 2007). The study by Heiwe, Clyne & Dahlgren (2003) highlighted “temporal stress” as a predominant feature of the participants’ experience of dialysis therapy. It referred to the time consumed to attend dialysis therapy and medical appointments. The participants were never able to do anything spontaneously because their treatment regime governed their time. Furthermore, their continuous need for rest stole their time and hindered their ability to complete their normal daily activities.

Kierans (2005) also highlighted the time-consuming nature of dialysis therapy. The study examined the narrative accounts of five people with ESRD in Ireland, who were either on dialysis or had a kidney transplant. The researcher stated that she specifically focused on the phenomenological character of renal failure. According to Koch (1995), it was essential at the outset for researchers using a phenomenological approach to discuss the different philosophical traditions that inform its methods. Kierans did not stipulate the philosophical or methodological assumptions underlying her phenomenological approach. However, based on the researcher’s discussion of the narratives, it was evident she had adapted a broadly psychological account of phenomenology.

There was no information provided in relation to the approach to data collection or analysis in the study. Moreover, there were no themes developed from the data. Therefore, this gave the impression that the narratives had merely been fitted onto a phenomenological discussion of the literature without being analysed in detail. The findings suggested that the participants on haemodialysis seemed to grieve for the time

they had lost due to the treatment. This included the time spent attached to the machine and time spent getting to and from the dialysis unit. According to Kierans (2005; p351), the participants highlighted their efforts to retrieve time by driving home from dialysis “at almost breakneck speeds, finding it hard to resist the temptation to win a little time back”.

The participants in the study by Curtin et al (2002) had to undergo three haemodialysis sessions each week, which lasted approximately four hours. They also expended additional time travelling to and from the dialysis unit, waiting to be attached to the machine, and waiting for their needle sites to stop bleeding at the end of treatment. The excessive time commitment of the treatment meant the participants had a continuous struggle to maintain any kind of normal lifestyle. Indeed, the re-arrangement of everyday activities was a significant factor in this struggle to maintain a normal life.

Hagren et al (2005) corroborated these findings in a study, which explored the experiences of forty-one patients on haemodialysis therapy in Sweden. There were twenty-six male and fifteen female participants in the sample. The researchers provided no evidence of the methodological approach used to carry out the research. However, qualitative, semi-structured interviews were used as a data collection technique followed by qualitative content analysis. The findings confirmed that haemodialysis therapy encroached on the participants’ time, and prevented them from engaging in everyday life. The participants expressed how the illness and treatment imposed marital, sexual, financial, work, and holiday restrictions on their lives. In particular, the intense tiredness they experienced contributed to these restrictions. As a result, some participants had withdrawn from active participation in society.

Other studies signified that the restrictive treatment regime of dialysis therapy caused some individuals to miss out on socialisation opportunities (Fisher et al., 1998; Sloan & Rice, 2000; King et al., 2002; Martin-McDonald, 2002). For instance, White & Grenyer (1999) used a phenomenological approach to explore the biopsychosocial impact of haemodialysis and peritoneal dialysis therapy on patients ($n=22$) in Australia. Qualitative interviews were conducted with eleven male and eleven female participants. The researchers did not describe the underlying principles of the phenomenological approach used in the study. However, they signified that they used a Husserlian

phenomenological approach to analyse the data. The findings of the study indicated that social isolation caused by the restrictions of dialysis therapy was a major concern for the participants in the study. Some participants had to leave their homes and re-locate to cities in an effort to be nearer dialysis facilities. Hence, they lost vital connections with social networks because of their illness and treatment.

Similarly, a study by Kaba et al (2007) illustrated the social impact of ESRD and haemodialysis therapy on the lives of twenty-three people in Greece. The researchers employed a grounded theory methodology incorporating qualitative interviews and qualitative data analysis. The participants indicated that the restrictions of the treatment regime of dialysis therapy disrupted all areas of their lives. Having to adhere to these restrictions led to social limitations for the participants. These limitations subsequently hindered the participants' ability to engage in family and community life. Moreover, the time consuming nature of haemodialysis therapy merely contributed to their inability to participate in many social events. Although Kaba et al (2007) used a grounded theory methodology there was little evidence that theory generation was achieved in the study.

Auer (2002) signified that ESRD and dialysis treatment altered the patient's body image, which made them feel different and unattractive. The skin discoloration of uraemia, premature ageing, and musculoskeletal deterioration caused by ESRD, contributed to an altered body image in these patients (Nagle, 1998). The invasive procedures required for the treatment of ESRD resulted in multiple scars and disfigurement, altering the patient's sense of identity and level of confidence (Auer, 2002).

Other factors that negatively impacted on the patient's body image included the appearance of a dialysis catheter or fistula, weight gain from excess fluid, increased abdominal girth brought about by peritoneal dialysis, and being connected to a dialysis machine (Auer, 2002; Curtin, Johnson & Schatell, 2004; Shirani & Finkelstein, 2004). For some individuals, the negative body image also had a negative effect on sexual functioning in intimate relationships (Auer, 2002; Shirani & Finkelstein, 2004).

The above discussion highlighted how ESRD and dialysis created many losses and lifestyle disruptions for the person. Various authors claimed that the lifestyle disruptions and losses induced by chronic illness were so profound that they culminated in a loss of self for the person (Bury, 1982; Charmaz, 1983; Sloan, 2002; Chesla, 2005).

2.6.2 THE LOSS OF SELF

The existing literature claimed that the loss of self was a significant form of suffering for the individual (Charmaz, 1983; Morse & Carter, 1996; Morse, 2001). The study by Charmaz (1983) highlighted how the experience of chronic illness resulted in a loss of the person's self-concept. The author described self-concept as the organisation of cognitive attributes that have become consistent over time. The person maintained the cognitive organisation of the self-concept through empirical validation in everyday life (Charmaz, 1983). The participants in the study signified that they lived a restricted life because of chronic illness. They existed in social isolation, had become a burden on others, and felt that their experience of illness was repeatedly misunderstood and discredited by others. Because of these experiences, the participants suffered a loss of their self-concept.

Correspondingly, in a personal account of the subjective experience of multiple sclerosis (MS), Toombs (1995) indicated that serious illness posed a profound threat to the self. As soon as the author was diagnosed with MS, she sensed that the illness represented a loss of personhood. From Toomb's perspective, her sense of self was intertwined with her personal and professional roles, and her goals and aspirations in life. However, MS threatened to disrupt these roles and aspirations because she required extra time off work, and had lost the energy to do basic everyday tasks. The limitations in life were perceived as failures and subsequently diminished the author's sense of self-worth.

The literature also highlighted how the lifestyle disruptions and losses associated with ESRD and dialysis therapy, culminated in a loss of self (Gregory et al., 1998; Curtin et al., 2002; Calvin, 2004; Jablonski, 2004; Murphy, 2006). For example, Jablonski (2004) indicated that ESRD and dialysis therapy affected all dimensions of the person's life.

Hence, these individuals had a subjective awareness of the disease on a continuous basis. Over time, the person's lifestyle altered dramatically in terms of health, psychological, social, economic, and family functioning (Jablonski, 2004). These lifestyle alterations caused the person to experience a loss of self-identity and self-worth.

Similar findings were reported in a study by Gregory et al (1998), which explored the perceptions of ESRD and haemodialysis therapy for thirty-six patients in Canada (Male=18; Female=18). A grounded theory methodology was employed incorporating semi-structured interviews and the constant comparative method of data analysis (Glaser & Strauss, 1967). This method of data analysis was appropriate for use within this research methodology.

The findings suggested that the disruptions of ESRD and dialysis caused the self to disintegrate. The researchers described the 'self', as an emotional/psychological state that altered with the evolving meanings of illness. The participants signified how their loss of control over renal function, and their dependence on the dialysis machine for survival created a loss of self-identity and self-worth. Some participants' physical health had declined and they experienced reduced benefits from dialysis therapy. These burdens contributed to their loss of self and created a barrier to their acceptance of the illness and treatment.

Curtin et al (2002) corroborated these findings, stating that the life-style limitations associated with ESRD and haemodialysis changed the person's self-concept. Therefore, to adapt to the illness and treatment, the person had to restructure the self through a series of self-affirmations.¹¹

The study by Nagle (1998) contended that the technology of haemodialysis therapy created a loss of the embodied self. The participants in the study indicated that their life on haemodialysis therapy was characterised by lost opportunities and restrictions in living. Hence, they were compelled to come to terms with a life that was different. The ability to accept a different life was a difficult aspiration to achieve for many

¹¹ These affirmations will be discussed later in the review in the section titled "the transformation process".

participants because it threatened the integrity of the self. Therefore, in an attempt to retain the embodied self, they struggled to be the same, while simultaneously being transformed by the technological aspects of care.

For example, some participants described the dialysis machine objectively and were adamant that it was not part of their identity. The need to be recognised as an individual and not just as a dialysis patient was an important feature in maintaining the embodied self. Because dialysis therapy was often distressing and uncomfortable, the participants tried to dissociate themselves from the treatment in order to preserve the self. However, this was not always possible, as the physical pain and discomfort experienced during haemodialysis therapy prevented total dissociation (Nagle, 1998). Like Nagle, other authors also reported how the participants' experience of being attached to the haemodialysis machine threatened the integrity of the self (Hagren et al., 2001; Giles, 2003, 2005).

The existing literature highlighted how the loss of self culminated in distressing emotional responses for the person (Gregory et al., 1998; Morse, 2001; Curtin et al., 2002; Calvin, 2004; Jablonski, 2004). For instance, the study by Kierans (2005) emphasised how the all-encompassing effects of ESRD created a loss of self amongst the participants. The disruptions caused by kidney disease made it necessary for the participants to negotiate their identity and role (Kierans, 2005). However, the unpredictability of the illness and treatment meant this was an ongoing activity, which provoked psychological distress.

Urien (2007) signified that the loss of self generated feelings of death anxiety within the person. In addition, Gregory et al (1998) conveyed the feelings of helplessness, humiliation, and inadequacy created by the participants' loss of self-worth. The following section will discuss the distressing emotional responses to ESRD and dialysis therapy.

2.6.3 THE DISTRESSING EMOTIONAL RESPONSES TO ESRD AND DIALYSIS

The qualitative literature highlighted the distressing emotional responses associated with ESRD and dialysis therapy. In particular, uncertainty and anxiety seemed to be the most prevalent emotional responses experienced within this patient group. Like the existing quantitative research, the distressing emotions were predominantly interpreted from a psychological or cognitive perspective within the qualitative literature.

2.6.3.1 Uncertainty & Anxiety

In the personal account of her subjective experience of chronic illness, Toombs (1995) conveyed the distressing emotional responses she experienced as a result of multiple sclerosis (MS). According to Toombs, the ongoing uncertainty was the most challenging emotion to manage. The course of MS was so unpredictable that feelings of uncertainty relentlessly haunted her throughout the illness. The pervasive uncertainty meant she could never ascertain what her condition would be like on a daily basis. Moreover, her ability to project forward future goals was diminished.

Living in the constant shadow of uncertainty was eventually so unbearable, that the author decided to reclaim some aspects of a normal life. This involved the suppression of uncertainty in an effort to function on a day-to-day basis. In particular, Toombs (1995) made a conscious decision to limit her thoughts of long-range goals. Rather than thinking of next month or next year, she concentrated on getting through one day at a time.

While it was difficult to continuously focus on the present, it was the only way to cope with the disruptions in life, created by the illness. More importantly, the predominant focus on the present allowed Toombs to concentrate her attention on actual problems, rather than potential ones. As a result, she was able to implement specific strategies to overcome immediate problems and regain some control over her life. By bolstering control, Toombs was able to balance the sense of uncertainty, which threatened to engulf her life.

Nonetheless, Toombs (1995) concluded her account with a poignant description of the difficulties she persistently faced, while she tried to repress the uncertainty and anxiety evoked by her illness:

There are thoughts that come unbidden in the night to reawaken my deepest anxieties. There is no way for me to look them in the face and remain intact. I must push them back. Back into the recesses of my consciousness. It is an act of will. I must think only of now. Of this day. Of this moment. Of what I have. Of what I can do. Of what gives me joy. Please, let me think only of this (p22).

Like Toomb's account, the existing qualitative research showed that the person with ESRD on dialysis tended to suppress the distressing feelings of uncertainty and anxiety. It seemed that these responses were so unpleasant for some individuals, that they used strategies to prevent themselves being overwhelmed by psychological distress. However, inevitably the distressing emotional responses could not be suppressed on a continuous basis. Consequently, the individual was confronted with the full intensity of the distressing emotions.

For instance, the study by King et al (2002) explored adaptation to diabetic renal disease in twenty people. The phenomenological approach used in the study emanated from a psychological or cognitive perspective similar to Smith's (1996) "interpretive phenomenological analysis" (IPA). In-depth interviews were conducted with ten male and ten female participants. The findings illustrated that stoicism or stoical endurance was the most dominant coping strategy used by the participants in the study. This coping strategy involved the participants carrying on with the illness as best they could, causing as little fuss as possible, and trying to look on the bright side. However, the experience of uncertainty that was inherent in the illness trajectory repeatedly undermined this stoical stance.

The authors found that relatively few participants in the study focused on the future. Instead, most insisted that they lived from day to day in an effort to consciously avoid thinking about the future. While they were well aware that their condition would probably deteriorate further, they knew that focusing on these issues was both unhelpful and frightening. Despite initially worrying about the future, several participants had decided to adapt a fatalistic outlook, which enabled them to carry on with their lives.

Hence, the feelings of uncertainty and anxiety were not permitted to overwhelm these participants, or undermine their stoic endurance strategies.

The avoidance or suppression of feelings of uncertainty and anxiety had a negative outcome for some participants. These participants avoided information related to their illness and treatment. However, the avoidance of information meant they lacked understanding about their condition, which subsequently induced greater anxiety and uncertainty.

Similarly, the participants in a study by Caress, Luker & Owens (2001) also illuminated this dynamic movement between the suppression and release of the distressing emotions associated with ESRD. The primary aim of this study was to explore the subjective meaning of illness in a sample of renal patients (n=405). The secondary aim was to explore the applicability of Lipowski's (1983) Meaning of Illness Schema as a framework to describe the participants' subjective experience of ESRD.

The participants' accounts illustrated that they were concerned about their prognosis, and were anxious about the possibility of future deterioration in their health. Despite this anxiety, "challenge" was the most frequent option selected from the schema by the participants. For some participants, challenge involved a determination not to give in to renal disease. They made references to bearing up, making the best of it, soldiering on, not complaining, and stoically accepting their situation. Participants also made fatalistic comments, which implied that they merely tolerated or put up with the illness. The participants knew they had no choice but to make the best of a bad situation. Therefore, their reports suggested that they continuously struggled to tolerate the physical and psychosocial challenges of ESRD and renal replacement therapy (Caress, Luker & Owens, 2001).

The uncertainty of life on haemodialysis was also emphasised in the study by Polaschek (2000). The participants reported concerns about the uncertainty and ongoing nature of dialysis therapy. As the time spent on dialysis passed, they had begun to recognise the relentless nature of ESRD and renal replacement therapy. The experience of repeatedly suffering the acute and long-term complications of ESRD and haemodialysis meant the participants could not ignore the chronic nature of their condition.

According to Polaschek (2000), the participants had come to realise that the development of the long-term complications of ESRD, were not necessarily avoided through effective dialysis therapy. Even though all the men considered that their treatment was going well at the moment, they all had experienced unexpected difficulties throughout the illness trajectory. Therefore, they were anxious and uncertain about potential problems that could arise in the future. The precariousness of their lives on dialysis and the prospect of a premature death was a significant source of uncertainty and anxiety (Polaschek, 2000).

To cope with the uncertainty of life on home haemodialysis, the participants strove to keep dialysis separate from their everyday lives. They achieved this by adapting a defined treatment regime on a weekly basis. They organised their lives rigidly around a set pattern of dialysis treatments. For example, some participants dialysed in the early hours of the morning or late at night. While this involved discipline and negotiation, it ensured that the participants could essentially segregate their everyday lives from the treatment. This defined segregation between life on dialysis and normal everyday life enabled the participants to maintain control, and get through each day, living with the uncertainty of the illness.

Kierans (2005) indicated that the participants on dialysis in her study focused on the imagined future with a kidney transplant because their lives were on hold. To re-iterate, this study examined the narrative accounts of five people, who were either on dialysis or had a kidney transplant in the Republic of Ireland. From the researcher's perspective, it was this future-oriented perspective that enabled the participants to tolerate the dialysis treatment regimen. However, one participant who had received a kidney transplant implied that she was still unable to anticipate a future. There was always the potential of developing complications, which could initiate transplant rejection, a return to dialysis, or death (Kierans, 2005).

Kierans suggested that the unpredictability of ESRD and the uncertainties attached to the future, contributed to discontinuities in the person's cognitive experiences. As a result, the person oscillated between states of emotional 'reprieve and distress' (Kierans, 2005; p350). Furthermore, his/her cognitive experience of time was disordered.

Consequently, the person continually focused on the present and tried to take one day at a time (Kierans, 2005).

The participants in the study by Curtin et al (2002) commented on the instability of their lives and the uncertainty regarding their futures. The participants were anxious because they were continuously confronted with the reality of death. The unpredictability of their lives hindered their ability to make decisions about their future. To tolerate the uncertainty, some participants refrained from setting long-term goals and commitments, such as marriage, children, and major purchases. For those who chose to set life goals, several-year timelines were the most they could manage. Since the participants in the study were on long-term haemodialysis therapy, some regretted that they had not planned more for their futures.

Embedded in the participants' accounts were their efforts to maintain control in the face of uncertainty (Curtin et al., 2002). Several participants addressed this dichotomy by concentrating almost entirely on the present. Their accounts suggested that they lived in the moment, and took each day as it came. The participants' decision to live in the present meant they were able to suppress the uncertainty, and reclaim some control over their lives (Curtin et al., 2002).

Like Curtin et al (2002), most authors referred to feelings of uncertainty and anxiety interchangeably within their discussions of the person's experience of ESRD and dialysis. However, Baines & Jindal (2003) specifically highlighted that anxiety occurred as a result of the person's realisation of the closeness of death. In their textbook *The Struggle for Life*, the authors provided a psychological perspective of kidney disease and transplantation. Throughout the book, the authors provided discussions and narrative accounts based on their long-term psychotherapeutic sessions with patients on renal replacement therapy. They indicated that the experience of chronic illness, such as ESRD served to heighten a patient's own death anxiety.

Correspondingly, Hutchinson (2005) indicated that dialysis therapy and kidney transplantation were effective treatments, which prevented the person from immediate death from ESRD. However, they did not return the person's life expectancy to that of the general population. Thus, the possibility of impending death was a source of

ongoing suffering and distress for these individuals. The distress was intensified when the death of a fellow dialysis patient occurred (Hutchinson, 2005).

Hagren et al (2001) reported similar findings in a study, which explored the experience of suffering from ESRD for fifteen patients in Sweden. Semi-structured interviews were carried out with seven male and eight female participants. The interview data were analysed using interpretive content analysis. The researchers indicated that they used a qualitative interpretive approach. However, they did not provide a clear connection to any methodological or philosophical framework in the study. Therefore, it is difficult to ascertain whether the data collection and analysis methods were consistent with the methodology.

The participants in the study indicated that the many hours spent connected to the haemodialysis machine gave them time for reflection about their illness and their expectations for the future. As a result, they became anxious about what would happen if haemodialysis did not work, or if they were unable to get a kidney transplant. These uncertainties threatened the participants' existence and confronted them with thoughts about death. The participants were constantly faced with the knowledge that they would not live forever. In particular, the loss of freedom, being forced to wait before dialysis therapy, and the lengthy dialysis sessions increased their awareness that precious time was running out.

The subsequent study by Hagren et al (2005) also illuminated an existential struggle embedded within the participants' experience of being on haemodialysis therapy. The researchers indicated that the dialysis machine played a significant role in this existential struggle. The dialysis machine infringed on time and dominated space, which served as a constant reminder to the participants that they were living on borrowed time. To overcome the uncertainty of living with ESRD, some participants in the study strove to "get through" each day of the illness as autonomously as possible. They also indicated that the ability to maintain a mental distance from thoughts about the illness played an important part in their ability to cope.

The participants in a study by Calvin (2004) emphasised how the continuous failure of their bodies, loss of independence, and additional co-morbid conditions of ESRD meant their lives were plagued by uncertainty. A grounded theory methodology was employed to explore the end of life decisions of twenty people with ESRD undergoing haemodialysis therapy in the USA. Qualitative interviews were carried out with eleven male and nine female participants. The researcher used the constant comparative method of data analysis (Glaser & Strauss, 1967), which was developed specifically for use within this research methodology. Based on the findings of the study, a substantive theory of “personal preservation” was formulated.

The participants in the study knew that their progressively declining health would affect their longevity. The prospect of impending death contributed to their feelings of pervasive uncertainty. Calvin (2004) declared that when the participants were faced with the uncertainty of life on haemodialysis therapy, they moved into a phase of “personal preservation”. Consequently, they used various strategies to block out the distressing feelings of uncertainty.

According to Calvin, death was always part of the participants’ lives, but they realised that death was ultimately out of their control. Therefore, several of the participants had dealt with this conflict between uncertainty and control, by distancing themselves from death. They blocked thoughts of death out of their mind, as this allowed them to maintain control over the distressing emotional responses associated with these thoughts (Calvin, 2004).

Baines & Jindal (2003) corroborated these findings and claimed that death anxiety created problems with adjustment because it initiated blocking responses, which served to avoid or deny the inevitability of death. By blocking feelings of death anxiety, individuals were essentially able to deny the reality of their death. However, the authors insisted that the suppression of anxiety created negative outcomes on the person’s adaptation to ESRD. For instance, some individuals took a “back-seat” or fatalistic approach to life. By taking this approach, they adapted the perspective that their life course was determined by the illness. During dialysis, these individuals were often very compliant, and adhered unquestionably with the routine and restrictions of dialysis therapy. They were often considered ideal candidates for transplantation. However, they

were also the patients who failed to develop any meaningful lifestyle on dialysis therapy. According to Baines & Jindal (2003), the time spent on dialysis for these people merely became “empty time” where they remained “stuck in the routine of nothingness that [became] increasingly static, desolate, and frustrated” (p154).

In a hermeneutical phenomenological study, Sloan (2002) indicated death was a real and anticipated part of the person’s experience of life on dialysis therapy. Using in-depth interviews, the researcher explored the experience of ESRD and dialysis therapy for fifty-six people from two large dialysis centres in the USA. An approach to data analysis based on the work of Benner (1994) and Diekelmann & Ironside (1998) was employed in the study. These authors specifically developed data analysis approaches for use in studies using a hermeneutical phenomenological methodology.

Sloan identified a central theme in the participants’ experience, which she labelled “dialysis is killing *me*”. The unpleasant symptoms and lifestyle disruptions associated with dialysis were so severe, that the treatment was seen by some of the participants as death inducing or “killing *me*”. As a result, the participants described the demands of a therapy, which seemed to offer survival but at the cost of living a normal everyday life (Sloan, 2002). According to Sloan, the existing literature in the area of ESRD predominantly viewed death from a biological perspective. This view simply assumed that without biological integrity, there was no survival. However, Sloan’s hermeneutical phenomenological analysis of the participants’ accounts highlighted that death was experienced, while there was still biological life.

The review of the qualitative literature highlighted that uncertainty and anxiety were the most prevalent distressing emotional responses to ESRD and dialysis therapy. Based on this literature, it appeared that the individual essentially oscillated between the release and suppression of these distressing responses. It is suggested that the dynamic movement between the suppression and release of anxiety and uncertainty, illustrated within this literature, was characteristic of the model of suffering, advanced by Morse (2001).

2.6.3.2 Morse's Model of Suffering

Morse and colleagues conducted extensive research on the concept of suffering over a number of years (Dewar & Morse, 1995; Morse & Carter, 1996; Morse & Penrod, 1999; Penrod, Morse & Wilson, 1999). Various research approaches were used in the studies, such as grounded theory, phenomenology, participant observation, and linguistic analysis. The samples in the studies consisted of male and female patients with a wide range of illnesses, including chronic illness.

Morse (2001) claimed that suffering was the subjective response to losses e.g. loss of self, loss of dignity, loss of movement, loss of an anticipated future, the loss of another. It consisted of two states: "emotional suffering" and "enduring". The author signified that emotional suffering was a distressed state where emotions were released. According to Morse (2001), when one emotionally suffered, s/he recognised the significance of what was lost and also recognised that the future was profoundly altered.

Morse (2001) indicated that during the release of emotions, some individuals felt they would psychologically disintegrate or literally fall apart. To avoid this psychological disintegration, the person protected the self by cognitively blocking and suppressing the unpleasant emotional responses. Morse (2001) described this strategy as enduring. It was a self-preserving strategy, which enabled the person to function on a day-to-day basis and get through the unbearable situation. Persons who were enduring focused on the present and this focus allowed them to get through each moment of the adverse event. By focusing on the present, the person effectively blocked out the past and the future. In its most extreme form, enduring disconnected the person from life. As a result, some individuals had no memory of the stressful event (Morse, 2001).

It is suggested that the unpleasant emotions of anxiety and uncertainty, represented in the qualitative literature on the person's experience of ESRD, symbolised emotional suffering. To avoid emotional suffering, the individuals suppressed the feelings of uncertainty and anxiety, which subsequently culminated in enduring. Indeed, specific features of Morse's (2001) description of enduring were represented within the literature, such as the suppression of emotions (King et al., 2002; Baines & Jindal, 2003; Calvin, 2004; Kierans, 2005), focusing on getting through the situation

(Polaschek, 2000; Caress, Luker & Owens, 2001), and concentrating on the present (Curtin et al., 2002; King et al., 2002; Kierans, 2005).

These responses to the distressing emotions of uncertainty and anxiety epitomised the concepts of emotional suffering and enduring, conveyed by Morse (2001). According to Morse, the process of suffering was not linear. There was a continuous movement back and forth between enduring and emotional suffering. In an earlier publication, Morse & Penrod (1999) concluded that feelings of uncertainty specifically generated a rapid movement between emotional suffering and enduring. The authors drew on the findings from previous studies, which delineated the concepts of enduring, emotional suffering, and hope in an effort to create links between these concepts (Morse & Doberneck, 1995; Morse & Carter, 1996). They claimed that uncertainty paralysed hope and induced discomforting emotional responses. Therefore, the individual merely existed in an emotional state, suffering his or her inability to move or act.

It seemed the uncertainty that surrounded the participants' future meant they had no other choice but to tolerate or endure the present. Therefore, uncertainty specifically encompassed a rapid movement between enduring and emotional suffering. When confronted with uncertainty, the person endured the present and was suspended, while hope was deferred. However, when the uncertainty continued overtime, the ability of some individuals to endure eventually failed and they fell back into emotional suffering (Morse & Penrod, 1999).

The dynamic characteristics of the model of suffering by Morse (2001), depicted the apparent oscillation between the release and suppression of uncertainty and anxiety, which was illustrated in the existing literature related to the person's experience of ESRD. However, this was somewhat different than the perspective of these emotions advanced in the existing quantitative research. As mentioned previously, the existing research, which examined the person's experience of ESRD and dialysis was primarily based on an empirical psychological framework. Within this research, the distressing emotional responses to ESRD tended to be assessed as part of larger studies, which investigated depression, adjustment, quality of life, and coping. For the most part, these studies interpreted the negative emotional responses to ESRD as evidence of depression, maladjustment, diminished quality of life, and an inability to cope.

However, by interpreting these unpleasant emotional responses in this way, it is suggested that this research effectively overlooked the potential significance of uncertainty and anxiety. Moreover, the dynamic characteristics, which formed the basis of the person's experience of these emotions, were also disregarded. This important contextual detail was applied by some of the qualitative studies on the person's experience of ESRD and dialysis therapy. This literature illustrated how the person essentially oscillated between the release and suppression of the unpleasant emotions caused by ESRD and dialysis. However, it is important to emphasise that these studies also adapted a primarily psychological perspective of these emotions.

According to Morse (2001), it was the acceptance of the lost past and the altered future that enabled the person to move beyond suffering. In particular, the work of hope enabled this progression to take place.

2.6.4 HOPE

The experience of hope was addressed in the existing research that pertained to the person with ESRD on dialysis. However, the concept of hope, along with other positive emotional responses, was predominantly examined from a psychological perspective, which used questionnaires. Within this research, hope was rarely addressed as an independent factor. Instead, it was interpreted as a secondary issue in relation to the broader concepts of adjustment, quality of life, and coping. For the most part, hope was deemed a positive influence on these broader issues. Conversely, hopelessness and other distressing emotional responses were largely interpreted as signs of depression, maladjustment, poor quality of life, and poor coping ability.

It is suggested that the primarily quantitative approach of this research overlooked significant contextual and background information embedded within the person's experience of hope. This resulted in a superficial description of the experience of hope for the person with ESRD on dialysis. The existing qualitative literature provided some of this contextual information, which allowed a more comprehensive understanding of the person's experience of hope to be articulated. In particular, the work of Morse &

Doberneck (1995), and Morse & Penrod (1999) facilitated a more in-depth understanding of the experience of hope for the person with ESRD on dialysis to be delineated. Hence, this work will be threaded intermittently throughout the following discussion.

Many qualitative studies highlighted how the ability to maintain hope or an optimistic outlook, enabled the individual to accept life with ESRD and dialysis therapy (Sloan, 1996; Nagle, 1998; Polaschek, 2000; Hagren et al., 2001; Al-Arabi, 2006). In particular, the hope of a kidney transplant offered these individuals the possibility of freedom from dialysis, and the chance of a normal life.

For instance, Rittman et al (1993) used a hermeneutical phenomenological methodology to explore the experience of six people living with ESRD. In-depth interviews were conducted with one female and five male participants. Data were analysed using a seven-stage approach by Diekelmann, Allen & Tanner (1989). This approach was appropriate for use within this study as it was specifically formulated for the analysis of data in hermeneutical phenomenological studies. The theme “maintaining hope” referred to the participants’ ability to see new possibilities in coping with ESRD. According to the authors, the experience of suffering from the pain and disability of ESRD was alleviated by hope, and enabled the participants to get through their daily lives. The participants expressed the hope of receiving a kidney transplant, the hope of returning to work, the hope that a new treatment would be discovered, and the hope that they would be around to watch their families grow up.

Similar findings were reported in a study by Ravenscroft (2005), which explored the experience of seven individuals with diabetic renal disease. In-depth interviews were carried out with two male and five female participants, followed by qualitative inductive analysis. While, Ravenscroft stated that she used a qualitative interpretive approach in the study, she did not describe the underlying methodological principles of this approach. Hope was discussed in two contexts in relation to the adjustment of the participants in the study. In the first context, hope was construed as positive thinking. It was focused on the present and was predominantly used in learning to manage the illness. In the second context, hope was reported as hope for a transplant. It was focused on the future and was predominantly used to facilitate acceptance of the illness.

The hope of a kidney transplant alone seemed to make acceptance of ESRD and dialysis easier, because it offered the participants the possibility of a normal life (Ravenscroft, 2005). This hope intensified for those who had a possibility for simultaneous kidney-pancreas transplantation. A kidney-pancreas transplant offered these participants the hope of life without dialysis and diabetes.

According to Ravenscroft (2005), the participants in the study differentiated between the hope elicited by the possibility of transplantation, and the hope engendered by positive thinking and reappraisal. This differentiation in patterns of hope was also highlighted in the study by Morse & Doberneck (1995), which delineated the concept of hope. The authors identified unique patterns of hope within various groups of individuals. These groups included six patients who were waiting for a heart transplant, nine patients who were being rehabilitated for spinal cord injuries, five patients who had survived breast cancer, and fifteen breastfeeding mothers who had returned to work.

Within each group, unique patterns of hope were illuminated. For instance, those awaiting heart transplants were “hoping for a chance” at life with a new heart. These participants knew that the only other alternative to transplantation was death. Therefore, they felt they had no option except to try to maintain hope, while they waited for the transplant to arrive. The patients with spinal cord injuries portrayed “incremental hope” and focused only on small gains and at one step at a time. The breast cancer survivors were “hoping against hope” because these women were continually forced to redefine hope when faced with each new challenge or barrier in their illness experience. Finally, the breastfeeding mothers described a form of “provisional hope” where they made contingency goals with repeated back up plans in case these goals had to be revised (Morse & Doberneck, 1995).

Like the study by Ravenscroft (2005), Morse & Doberneck identified different patterns of hope, which existed within different groups of individuals. They also identified components that were universal to the subjective experience of hope in all groups. For instance, they described the ability to brace oneself for negative outcomes, as a universal component of the experience of hope. From the authors’ perspective, hope always existed with the threat of failure. Therefore, the role of despair was significant in

the participants' ability to reformulate hope, and revise hope goals. However, this potential negative alternative was rarely discussed in the literature related to hope (Morse & Doberneck, 1995).

Greene (1984) subscribed to this view indicating that it was overly simplistic to assume that hope was essentially and always good or positive. The author suggested that within the person's complex psychology, hope was accompanied by the dread of hopelessness, or a fear that the desired goal would not be attained. Therefore, when hope was frail, feelings of hope tended to give way to more negative feelings, such as despair and depression (Greene, 1984).

The studies by Morse & Doberneck (1995) and Morse & Penrod (1999) also illustrated this dynamic movement from the positive emotions of hope to the negative emotions of hopelessness and despair. The authors noted that a considerable time elapsed between the participants selecting and attaining a goal. While the person was initially hopeful, s/he had to wait and endure the time lapse until the goal was attained. Hence, Morse & Doberneck (1995) described a "determination to endure" as a universal component of hope, which allowed hope to be sustained. The ability to endure enabled the participants to suppress negative thoughts and emotions associated with their situation, and hold onto hope.

However, as Morse & Doberneck (1995) pointed out, it was difficult for some participants to continuously suppress the negative emotional responses evoked by the illness or stressful situation. At these times, they oscillated into emotional suffering and experienced distressing emotional responses such as uncertainty, hopelessness, despair, and depression. For example, some breast cancer survivors conveyed that when they were confronted with each new challenge or barrier in their illness, they reverted to enduring. They struggled continuously to suppress the negative thoughts and emotions and focused on the preservation of the self. Alternatively, others were unable to see a goal or path out of the repeated setbacks. Therefore, they fell back into the hopelessness and despair of emotional suffering.

The experience of hope described by the other participants in the study also portrayed how critical events in their illness or situation created this movement between emotional suffering and enduring. In particular, the patients who were awaiting a heart transplant had no alternative except to maintain a positive attitude and endure the waiting time for a donor to be found. However, one young man who was awaiting a heart transplant recalled a time when he lost hope. He described the despair when he realised that the heart he was supposed to receive was not available for him.

According to the authors, this oscillation between emotional suppression (enduring) and emotional releasing (emotional suffering) formed the basis of the concept of hope (Morse & Doberneck, 1995; Morse & Penrod, 1999). These dynamic characteristics were also identified within the experience of hope, conveyed in the qualitative literature related to the person's experience of ESRD. This literature illuminated that potentially negative thoughts, feelings, and emotions were embedded within the individuals' experience of hope. Consequently, the experience of hope was not static for these individuals. Rather a vacillating movement accompanied the experience of hope, which consisted of the release and suppression of the unpleasant emotional responses associated with ESRD.

For instance, the participants in the study by Calvin (2004) spoke about being hopeful, expecting favourable outcomes, and wishing for longevity. They recognised the potential brevity of their lives but persisted in their hope for a long, high-quality life. The ability to make the best of the current situation was significant for the participants. Despite the difficulty of their lives with ESRD, they described their willingness to maintain an optimistic outlook. Some complained about the negative adjustments they had to make because of ESRD and dialysis. Nonetheless, their zest for life still prevailed.

Similarly, "staying alive" was a category identified in the study by Al-Arabi (2006), which referred to the participants' efforts to cope with ESRD and dialysis therapy. The participants expressed their hope for a kidney transplant or a cure for ESRD. They used various strategies, which motivated them to continue with dialysis therapy, until a kidney transplant or a cure was found. The support of others, the ability to accept the treatment as part of life, and trust in God were described as strategies, which enabled

the participants to endure the treatment. These strategies had given them the strength to get through each day, and remain hopeful of healing.

In the study by Polaschek (2000), the participants expressed that the hope of a kidney transplant enabled them to cope with their illness and treatment. The participants described how the ability to look forward to a transplant, enabled them to endure the uncertainty and relentless nature of ESRD and haemodialysis therapy. The possibility of a kidney transplant offered the participants the hope that dialysis was a temporary problem. However, according to Polaschek (2000) the optimism of the participants merely reflected the optimism of the healthcare team in relation to kidney transplantation. The healthcare team had informed the participants that they could expect to receive a transplant within a few years. Despite having waited for many years, some of the participants remained confident that they would be transplanted shortly.

In contrast, two of the participants had begun to realise that dialysis could continue indefinitely into the future. This contributed to the experience of uncertainty, which accompanied life on renal replacement therapy. However, apart from these two participants, the men showed almost no recognition of the degree of uncertainty, which surrounded transplantation. They had no awareness of the potential complications of the treatment and the possibility that it could fail. Therefore, although their hope of a transplant was objectively unrealistic, it provided a necessary coping mechanism for the participants to deal with the uncertainties of life on dialysis (Polaschek, 2000).

The findings from the study by Polaschek (2000) demonstrated the dynamic movement between emotional suffering and enduring, which was embedded within the participants' experience of hope. Other studies also portrayed this oscillation between emotional suffering and enduring, which formed the basis of the experience of hope for individuals with ESRD on dialysis therapy.

For example, a study by Lindqvist, Carlsson & Sjoden (2000) described the perceived consequences of illness and treatment among eighty-six patients with ESRD. There were fifty-one male and thirty-five female participants in the sample who were either on haemodialysis therapy, peritoneal dialysis therapy, or had received a kidney transplant. Unstructured interviews and content analysis were the research methods used in the

study. The researchers identified the overall research approach taken in the study as exploratory-descriptive. However, they did not address any methodological or philosophical considerations in relation to this approach.

A category labelled “hope/fulfilled dreams” was identified within the participants’ accounts. The participants conveyed the hope that everything would get better and the hope of a kidney transplant. However, there were mixed feelings associated with the participants’ hope of a transplant. For some participants, the possibility of transplantation was identified as the greatest source of hope for a normal life. However, other individuals expressed feelings of dread in relation to transplantation because they had a negative experience of the procedure in the past, and were aware of the potential complications that could arise.

Using a grounded theory methodology, Weems & Patterson (1989) sought to identify the concerns of fourteen candidates awaiting renal transplantation, and to identify coping strategies used during the wait. Qualitative interviews were conducted with ten male and four female patients who were within ten days after renal transplantation. The constant comparative method of data analysis (Glaser & Strauss, 1967) was used. This approach to data analysis was suitable for this study, as it was specifically developed for use in studies using a grounded theory methodology.

Based on the findings of the study, the major coping strategy used by the participants was tempered hope. The researchers used the term “tempered” because the participants’ hope was moderated or weakened by the uncertainties inherent in the waiting process. The participants’ expressed their experience of wavering between the positive emotional state of hope and the distressing states of uncertainty, anxiety, hopelessness, and despair.

When the participants initially got through the evaluation to get on the transplant waiting list, they developed a sense of hopefulness that sustained them during the wait. Some participants seemed to be aware that a kidney transplant might never become available or was far off into the future. Therefore, as a protective mechanism, they tempered their hope with the knowledge of the reality of the situation. However, at the same time, signs of hopefulness were reflected in participants’ arrangements to ensure

they did not miss the phone call informing them of a potential donor kidney (Weems & Patterson, 1989).

The participants recalled how living with the relentless uncertainty was a major burden, while they had waited for a kidney transplant. They were confronted by the uncertainty of the surgery itself and the inability to ascertain the post surgical outcome. The uncertainty intensified at critical junctures in the waiting period. For instance, when they felt unwell, when a fellow patient either received or rejected a kidney transplant, when they missed a phone call related to an available kidney, or when the waiting period became lengthy. These critical incidents challenged their usual coping strategies and caused the participants to become psychologically distressed. At these times, the participants would attempt to draw from this source of tempered hope to get through the adversity of life on dialysis (Weems & Patterson, 1989).

While waiting, some participants were satisfied to adopt a fatalistic attitude to cope with the uncertainty and made statements like “when the time comes, it will come”. Others wanted more certainty and calculated a potential time to expect the transplant surgery based on the information received from the healthcare team. However, these strategies were not always sufficient in dealing with uncertainty.

As the time passed, the possibility of eventually receiving a transplant became more remote. In particular, when the date the participants figured they would receive a kidney transplant passed, they began to wonder if they would ever receive a kidney transplant. The earlier optimism was diminished, as the participants began to wonder if their names were still on the list or if they had been forgotten. Some blamed the nephrologists for the long wait. Others avoided thinking about it in an effort to block out the distressing reactions induced by the persistent waiting (Weems & Patterson, 1989).

Correspondingly, a study by Sloan (1996) also exemplified how the distressing emotions of uncertainty and fear formed the background to the person’s hope of receiving a transplant. This hermeneutical phenomenological study explored the medical treatment decisions for patients with ESRD and their families in the USA. The participants were either on haemodialysis therapy or had a kidney transplant at the time of the interviews. Sloan used a hermeneutical approach to data analysis (Diekelmann,

Allen & Tanner, 1989) to understand the reasons behind the participants' decision to seek kidney transplantation.

Most of the participants in the study had decided to be considered for transplantation in an effort to be freed from dialysis therapy. One of their greatest hopes was that their lives would become more normal. However, beneath their hope of receiving a kidney transplant was the uncertainty of the potential complications associated with the procedure. For instance, the participants contemplated the possibility of repeated surgeries, pain, and the need for continuous medical intervention prior to making the decision to avail of a transplant. A major concern for the participants was the possibility of transplant rejection, resulting in a return to dialysis therapy. The grim possibility of not surviving the process of transplantation was also embedded in their accounts (Sloan, 1996). Because of these concerns, some participants decided to forego the opportunity to receive a kidney transplant. Alternatively, the participants who decided to avail of the treatment described their experience of endlessly waiting for the transplant that never happened, or happened for someone else.

In the subsequent study by Sloan (2002), the participants also described their hope of eventually receiving a kidney transplant. However, financial difficulties were reported as a source of uncertainty in their decision to consider transplantation. According to Sloan, some individuals simply did not have the appropriate healthcare insurance to cover the costs of the immunosuppressive therapy and the medical treatment required for kidney transplantation in the USA. The author emphasised that it was unknown how many of the transplant failures in the USA occurred because of individuals trying to "stretch [their] medications to the end of the month" (p146).

Indeed, a recent study by Denhaerynck et al (2006) compared the adherence with immunosuppressive drugs amongst kidney transplant recipients in the USA ($n=1563$) and Europe ($n=614$). The findings indicated that there was a higher rate of non-adherence with immunosuppressive medication in the US sample, than in the European sample. Like Sloan, the researchers claimed that differences in healthcare characteristics, such as health insurance coverage, and the reimbursement of expenses for drugs and medical treatment, were important factors in the higher rate of non-adherence in people in the United States.

As pointed out in the above discussion, the existing literature demonstrated that hope was not a static experience or some positive end-state for the person with ESRD on dialysis therapy. It did not merely consist of the person setting goals and passively waiting for these goals to be achieved. Instead, the experience of hope triggered a dynamic movement between the suppression and release of the distressing emotional responses associated with ESRD. In particular, the work on the concept of hope by Morse & Doberneck (1995) and Morse & Penrod (1999) facilitated the dynamic characteristics of the experience of hope, to be illuminated within the qualitative literature. It allowed the oscillatory movement between enduring and emotional suffering, which was embedded within the person's experience of hope to be demonstrated. Enduring enabled the person to sustain hope by actively blocking out or suppressing the negative emotional responses to ESRD. Alternatively, emotional suffering involved the release of these distressing emotions, which occurred when hope was undermined.

Morse (2001) affirmed that after the cyclic movement between enduring and emotional suffering, the person was eventually ready to accept the lost past and altered future. Acceptance moved him/her beyond suffering and onto the reformulated self. The notion of reformulating the self was contained within the existing literature on the person's experience of ESRD. However, it was more commonly identified as a "process of transformation".

2.6.5 THE PROCESS OF TRANSFORMATION

The qualitative literature indicated that "transformation" was an essential feature of adjustment or adaptation to ESRD and dialysis. Transformation was described as a process where the self was re-defined and re-structured. This process enabled the person with ESRD achieve a new sense of normality, thus allowing the effects of the illness to be integrated into his/her life. While the notion of transformation was associated with adjustment to ESRD and dialysis, it differed considerably from our current understanding of this concept. Unlike the perspective of adjustment advanced in the existing quantitative literature, transformation was not an end state. The process was not completed with the attainment of normality in physical and psychosocial functioning.

Furthermore, transformation did not consist of the person progressing through a linear process, which eventually ended in successful adjustment.

Transformation, as the experience of adjustment to ESRD and dialysis, was a long and drawn out process. It involved the person struggling continuously throughout the illness trajectory to re-define the self, integrate the limitations of the illness into their lives, and adapt to a new normal. Transformation was not a static process but was ongoing and dynamic, and occurred throughout the illness trajectory. In particular, the ability to achieve autonomy, independence, self-mastery, self-care, and so forth were identified as integral to the success of this process.

For instance, the study by Gregory et al (1998), which explored the person's experiences of ESRD and haemodialysis therapy, highlighted the re-definition of self as a dominant category. Despite the uncertainties inherent in the illness and treatment, the participants strove to achieve a new sense of self. The researchers claimed that this "new sense of self" was an emotional/psychological state that fluctuated with the evolving meanings of illness, and the perceived quality of supports. It involved the participants deriving satisfaction from the things they could still do, and by living in hope for a better future with a kidney transplant. These strategies acted as a buffer against the distressing emotional responses evoked by the illness and treatment.

The accounts of several participants signified that the redefinition of the self was not a passive endeavour (Gregory et al., 1998). It involved a continuous struggle to come to terms with the illness, accept the treatment restrictions, and deal with the uncertainty of life on dialysis. The participants described their ability to eventually adapt to the physical, emotional, psychological, and social changes incurred by the illness and treatment. Their gradual adjustment to a new sense of normality was achieved through a process of transformation from the remembered "old self" to the "new self".

Gregory et al (1998) emphasised that transformation into the new normal was not an end state for the participants. Rather, the continuous changes overtime in physical functioning and activity tolerance meant the participants were continuously challenged to transform the self. In addition, the complications specifically associated with

haemodialysis therapy, which included problems with access, cramps, hypotension, and delays, made adjustment to the treatment regime a continuous struggle.

The constant emotional and psychological adjustments to changing health states made it difficult for some participants to adapt a positive sense of self (Gregory et al., 1998). Nonetheless, most participants in the study indicated that they strove to maintain a positive attitude about the future. In particular, the ability to maintain responsibility for self-care was an important aspect in the transformation process. By performing self-care activities, the participants continuously strove to achieve and maintain an acceptable level of normality.

Similarly, the participants in the study by Nagle (1998) expressed multiple personal transformations, which culminated from living with ESRD. The participants described their experience of “coming to terms” with the losses and limitations imposed on their lives by ESRD and haemodialysis therapy. This involved trying to sustain a sense of normality by accommodating the restrictions of their illness and the treatment.

The participants experienced a loss of their personhood because of ESRD and dialysis. However, they worked to redefine their personhood in an effort to integrate the technology of haemodialysis more seamlessly into their lives. In particular, the participants described the difficulty of having to accept machine dependency, while maintaining autonomy in every other aspect of their lives. They described how the vigilant monitoring of their bodies, combined with active involvement in decision-making about their care were significant factors in maintaining autonomy.

For instance, the participants’ lives were constructed around the self-management of their illness. They independently managed the dietary and fluid restrictions, the medication regime, and the monitoring of the complications associated with ESRD and dialysis. The ability to participate in a normal life was a continuous challenge for the participants. However, they pushed their physical limits in an effort to retain significant elements of their former selves (Nagle, 1998).

Correspondingly, a phenomenological study by Giles (2003) found that the life-world of four people was transformed by home haemodialysis therapy. The phenomenological methodology employed in the study was based on the work of Van Manen. According to Van Manen (1997) “phenomenological research is the explication of phenomena as they present themselves to consciousness” (p9). Therefore, this approach to phenomenology was largely founded on a psychological or cognitive perspective. Semi-structured interviews were conducted with the participants and data were analysed using an approach by Van Manen (1997).

The findings of the study indicated how ESRD and haemodialysis therapy had transformed the bodily experience of the participants. The need for access to the bloodstream for dialysis meant the participants had lost control over their bodies. In this way, the body had essentially become a site for medical intervention. Despite the distress caused by their experience of haemodialysis therapy, the participants strove to retain control and sovereignty over their bodies. This ongoing process facilitated a transformation of the lived-body, as well as the life-world of the participants (Giles, 2003).

Curtin et al (2002) also described the process of surviving on long-term dialysis therapy, as a transformational experience. According to the researchers, the process of transformation, illustrated by the participants in their study, corresponded closely to that described by Paterson et al (1999). Paterson et al (1999) claimed that the existing literature contained various perspectives of transformation in chronic illness. However, the process was generally deemed to involve a restructuring of the illness experience and/or a restructuring of the self (Charmaz, 1983; Morse, 1997, 2001; Ohman, Soderberg & Lundman, 2003). The authors conducted a qualitative study, to specifically explicate the processes of transformation in a group of individuals with Type 1 diabetes ($n=22$) (Paterson et al., 1999).

Transformation was described as an evolutionary activity, which involved the participants responding to the demands of the illness. It was viewed as a cognitive process, which evoked affective or emotional responses. According to the participants, transformation involved the conscious decision to assume control of the self-management of diabetes. This decision resulted in significant changes in the

participants' values, beliefs, assumptions, and daily practices in living with their illness. In particular, it led to the realisation that the participants themselves were the experts about their disease, and not the healthcare professionals or significant others.

Like the previous studies, Paterson et al (1999) highlighted that that the process of transformation did not consist of an end state. Instead, the participants' accounts implied that the process was never complete and continued repeatedly throughout the illness trajectory. These individuals were regularly faced with additional complications associated with their disease and its treatment. Hence, transformation was required on an ongoing basis to renegotiate a balance after each complication.

Based on these findings, Paterson et al recommended that transformation should not be viewed as representative of effective adjustment to illness. Rather, the notion of transformation should be used as a way to understand the processes experienced by the person with a chronic illness, such as diabetes. By interpreting transformation in this way, retreats in the transformation process caused by additional complications or setbacks, should not be viewed as a regression or failure. Rather, they should be understood as a normal and necessary part of the transformation process (Paterson et al., 1999).

The study by Curtin et al (2002) also indicated that surviving on long-term haemodialysis therapy was a transformational experience similar to that identified by Paterson et al. The participants indicated that successful transformation of the self involved the comprehensive, active self-management of life with ESRD and haemodialysis therapy. Every participant was involved in the self-management of many aspects of his/her illness and treatment. The ability to have control over their lives, maintain a sense of independence, and accept responsibility for their treatment was mentioned repeatedly as part of the process of transformation.

According to Curtin et al (2002), the process of transformation was long and demanding on the participants. However, all participants signified that the ability to retain at least some part of their pre-dialysis identity was an important feature in the transformation process. The researchers identified two distinct sets of activities, which were involved in achieving the transformed self: (a) adaptation to the changed self through a series of

self-affirmations (b) adaptation to the changed circumstances: coming to terms with permanent kidney failure.

The participants achieved adaptation to the changed self through various self-affirmations. For instance, all participants affirmed that they wanted to live. However, they knew that to keep living, they had to accept the limitations in lifestyle caused by the treatment regime of dialysis. Accepting these limitations enabled the participants to restructure their sense of self in order to survive on dialysis therapy.

Although the effects of ESRD and dialysis challenged the participants' sense of self, they still managed to retain an essential part of their identity. The affirmation "I am still me" enabled the participants to separate their individual identity from the disease (Curtin et al., 2002). Participants described their experience of taking ownership of their lives and separating out the self from the illness. The participants' lives were seriously disrupted by ESRD and dialysis therapy. Despite these lifestyle limitations, the participants were able to retain significant characteristics of selfhood and affirmed that they were still too worthwhile to die. These positive and conscious affirmations highlighted the importance of self-worth in the process of transformation when confronted with ESRD.

The final affirmation was related to self-efficacy (Curtin et al., 2002). Bandura (1997) claimed that a person's decision to carry out a particular health related behaviour was influenced by the person's beliefs about efficacy. According to the author, there were two types of efficacy beliefs, which included outcome efficacy, and self-efficacy.

Outcome efficacy referred to the person's belief about whether his/her behaviour would result in an effective outcome (e.g. taking medications will reduce my phosphate level and so prevent the discomfort of pruritis/itching). Self-efficacy referred to the person's belief about whether they were able to carry out the behaviour (e.g. I am confident that I can manage my dietary and fluid restrictions everyday). The person's perceived self-efficacy influenced the person's health-related behaviours (Bandura, 1997).

The study by Curtin et al (2002) found that the affirmation of self-efficacy or “I am in control” was an important feature in the transformation of the self. The participants believed that they could retain control over many aspects of their lives, and this was an essential part of their adjustment to ESRD and dialysis. However, for several of the participants, it was a struggle to maintain control over their healthcare in addition to their everyday roles and responsibilities. The need to be well informed about the consequences of the illness on their lives was an important factor in regaining control. These positive self-affirmations were an essential part of the process of successful transformation of the self. They enabled the participants to integrate the limitations of ESRD and dialysis into their lives.

The second activity included in the process of transformation involved coming to terms with ESRD (Curtin et al., 2002). The participants had to come to terms with major life experiences during the transformation process. As mentioned previously, the participants described the uncertainty of their lives and the close proximity of death.¹² It was a major hurdle for the participants to come to terms with feelings of death anxiety, while simultaneously participating in life. However, the participants’ stark awareness of their own mortality seemed to motivate them instead of immobilising them. Indeed, several of the participants appeared to have confronted the possibility of their death, addressed it, and moved on in a positive manner (Curtin et al., 2002).

As previously mentioned, the ability to maintain control was essential in the process of transformation (Curtin et al., 2002). However, the participants’ accounts signified that uncertainty was the converse of control. Hence, coming to terms with ESRD meant the participants had to reconcile their need for control with the uncertainties inherent in the illness and treatment. One way that the participants overcame this dichotomy was to focus entirely on the present. By making the definitive decision to live in the present, the participants were able to alleviate some of the uncertainty, which accompanied ESRD and regain a sense of control over their lives.

¹² See page 53 for the previous discussion on uncertainty in the study by Curtin et al (2002).

If we recall, the person's predominant focus on the present was described earlier in relation to Morse's (2001) work on the concept of enduring.¹³ When enduring, the person focused on the present in an effort to get through an unbearable situation (Morse, 2001). Based on these findings, it is suggested that the ability to endure may have been a significant feature in the process of transformation for the participants in the study by Curtin et al (2002). By focusing on the present, the participants were able to limit the distressing feelings of uncertainty and continue to get on with life.

According to Curtin et al, the participants' lives were constrained in many different ways by ESRD and dialysis. Coming to terms with such constraints represented a major step in the transformation process and adjustment to ESRD. Like the findings of the study by Paterson et al (1999), the participants tried to merge elements of their past lives with the realities of their present lives on dialysis. This enabled them to form an identity that fitted the confines of their illness, and simultaneously prevented distress (Curtin et al., 2002).

For instance, some participants who had been active in the past described how they engaged in more passive pastimes. Other participants spoke of how they had learned to enjoy the small things in life. Previous studies on the transformation/reformulation of the self in chronic illness have also represented this merging of old and new realities (Charmaz, 1983; Morse, 1997; Paterson et al., 1999; Morse, 2001; Ohman, Soderberg & Lundman, 2003).

Curtin et al (2002) signified that the intrusiveness of dialysis therapy made ESRD a particularly difficult illness to accommodate. However, the participants in the study tried hard to prevent dialysis from becoming the principal focus of their lives. While they perceived dialysis as a chore, the participants were well aware that without the treatment they would not survive. Hence, some spoke of their gratitude for the technology, while others described a kind of love hate relationship with the machine.

¹³ See page 57 for the previous discussion on the concept of enduring.

Coming to terms with the repeated set backs of ESRD and dialysis (e.g. vascular access problems, bone disease, infections, cardiovascular disease) was a relentless challenge for the participants. They stated that they were unprepared for the harsh reality of the repeated setbacks, which occurred throughout the course of the disease. These setbacks took a toll on the participants over time. However, with energy, endurance, and courage, they had been able to struggle along toward the next challenge (Curtin et al., 2002).

Overall, the participants viewed successful transformation as the comprehensive and active self-management of their lives with kidney disease. The process included efforts by the participants to change what was changeable, control what was controllable, and to actively struggle to come to terms with the consequences of ESRD (Curtin et al., 2002).

Additional studies also highlighted the importance of characteristics such as autonomy, self-care, self-mastery, and self-efficacy in the person's ability to transform the self and adapt to ESRD and dialysis. For example, a more recent study by Curtin, Johnson & Schatell (2004) illustrated how the ability to maintain autonomy and control enabled some individuals to adapt to ESRD. In particular, the study sought to identify the domains and dimensions of self-management experienced by a group of eighteen people on peritoneal dialysis in the USA. Like the previous study by Curtin et al (2002), Curtin, Johnson & Schatell used an exploratory-descriptive research approach but did not address specific methodological considerations regarding this approach. Semi-structured interviews were carried out with ten male and eight female participants followed by qualitative content analysis.

The participants in the study were engaged in the self-management of their illness and treatment. According to the researchers, self-management in the study was composed of two domains. The first domain included the issue of autonomy and control in healthcare, while the second domain was related to the participants' need for normality in their lives.

All of the participants in the study talked about the significance of autonomy in their ability to manage their own treatment. There were three features of the participants' perception of autonomy: (1) Being an active collaborator in decision-making regarding their treatment and care, (2) Being able to manage the treatment independently, and (3) Maintaining self-efficacy (Curtin, Johnson & Schatell, 2004).

All of the participants described their efforts to maintain autonomy by becoming active partners in their health care. They emphasised the importance of being fully involved in the decision-making component of their care. The self-care required for the peritoneal dialysis treatment regime meant the participants implemented many decisions in relation to their own care. The participants described how they managed the treatment independently on a daily basis. Although the dialysis regime was complex and highly technical, it was deemed a normal part of everyday life to the participants. They independently managed the continuous process of "connections" and "disconnections" required during peritoneal dialysis. They also cared for their peritoneal catheter sites, recognised and prevented complications, and managed their dietary and fluid restrictions (Curtin, Johnson & Schatell, 2004).

Fifteen of the eighteen participants in the study spoke of self-efficacy. To reiterate, self-efficacy referred to the individual's belief as to whether they were able to carry out the necessary behaviours to manage the illness and/or treatment independently (Bandura, 1997). The participants in the study possessed positive self-beliefs and performance skills. They were confident about the behaviours that led to positive health outcomes, and were also confident in their ability to carry them out (Curtin, Johnson & Schatell, 2004).

The quest for a normal life was also very important to the participants in the study. They pushed themselves to incorporate the disease and treatment into their everyday lives, and achieve a new sense of normality. This process was constituted by three components: (1) the achievement and maintenance of flexibility and freedom, (2) perceptions of body image, and (3) interpretations regarding the severity of their illness.

All the participants in the study described the freedom, the mobility, and normality that peritoneal dialysis offered them. The flexibility of the treatment regime enabled them to adjust their dialysis schedule to fit their work and social lives. Consequently, the participants were able to maintain their normal roles and responsibilities in everyday life (Curtin, Johnson & Schatell, 2004).

The participants were very concerned about the changes in their bodies. They mentioned issues such as the appearance of the dialysis catheter, an excessively swollen abdomen, and weight gain. Despite the loss of confidence incurred by these changes, the participants had been able to confront, and move beyond their body image concerns. They simply decided that their altered body image was not going to interfere with their lifestyle.

According to Curtin, Johnson & Schatell (2004), the participants seemed to have experienced minimal intrusions in their lifestyle. Therefore, they interpreted their illness quite positively, and appeared to be living full and productive lives around the treatment. Indeed, some described dialysis quite casually as “something I have to do, like brushing my teeth”, or “an inconvenience” (p621). The participants’ interpretation of ESRD and peritoneal dialysis differed considerably from the experiences of the participants on haemodialysis therapy in the previous qualitative study by Curtin et al (2002).

In particular, the participants on haemodialysis therapy spoke frequently of the regular setbacks, acute episodes, and complications associated with haemodialysis therapy. Therefore, although these participants also managed their illness and treatment successfully, they definitely considered themselves as having a serious chronic illness. In contrast, the participants on peritoneal dialysis did not see sickness as an integral part of their identity. They did not report the frequent setbacks and complications of ESRD and dialysis. Indeed, the only participants on peritoneal dialysis who described themselves as being sick actually were sick with a complication or co-morbid illness episode.

Similarly, the participants on peritoneal dialysis did not feel at particular risk of impending death. These findings were also in sharp contrast with the participants' descriptions of haemodialysis therapy in the previous study by Curtin et al (2002). The participants in this study reported that the uncertainty of ESRD and haemodialysis therapy meant that the spectre of death was continuously hanging over them (Curtin et al., 2002).

It appeared that through hope, optimism, and a positive outlook, the participants on peritoneal dialysis were able to balance the need for autonomy and control against the uncertainties inherent in ESRD. This accomplishment contributed to their ability to achieve self-management and preserve many elements of a normal life in spite of chronic illness (Curtin, Johnson & Schatell, 2004).

In addition to the studies discussed above, many other studies have highlighted the significance of maintaining autonomy, control, self-management, independence, and normality in the adjustment to ESRD and dialysis therapy (Hagren et al., 2001; King et al., 2002; Curtin, Johnson & Schatell, 2004; Giles, 2005; Ravenscroft, 2005; Polaschek, 2007). Agich (2003) contended that the understanding of autonomy in the Western world assumed that independence, self-sufficiency, self-control, and non-interference were important characteristics for the individual. However, because this view of autonomy placed such emphasis on independence, any degree of dependence was viewed as a deficiency on the part of the individual (Agich, 2003). Various authors conveyed how the person's forced dependence on dialysis for survival undermined his/her capacity to achieve a sense of personal autonomy.

2.6.5.1 The Paradox of Autonomy

Some of the diabetic patients in the study by Paterson et al (1999) claimed that there was a downside to the transformation process. These individuals experienced a tension between the need to be autonomous, while simultaneously feeling alone and solely responsible for the self-care of their illness. The determination to maintain the transformed self was sometimes a source of interpersonal conflict. This was particularly evident when the healthcare team ignored their needs and wishes. On these occasions,

the participants were confronted with the paradox of autonomy and dependence that was inherent in the process of transformation.

The accounts of the participants in the study by Polaschek (2000) also illustrated a complex interrelationship between autonomy and dependence. The participants were competently managing their haemodialysis treatments at home. Indeed, they felt that the self-management of their treatment allowed them to maintain a more normal life than people on hospital-based haemodialysis therapy. For example, they did not have to waste time travelling to and from the hospital for dialysis, or have to wait for a machine to become available before treatment began (Polaschek, 2000).

However, there were other aspects to the participants' lives, which repeatedly reminded them of their dependence on haemodialysis therapy. The unpleasant residual symptoms of ESRD, which arose when they needed dialysis, reinforced their dependence on the treatment. Although the participants had to be self-caring and autonomous in the management of their treatment regime, they knew the dialysis machine ultimately had control over them. To survive, they had to accept their dependence on the technology of dialysis. Furthermore, most of the men in the study were dependent on their wives or partners to assist them with the dialysis procedure. These aspects of haemodialysis therapy reinforced the altered interrelationship between autonomy and dependence that existed for the participants in the study (Polaschek, 2000).

According to Polaschek (2000), the dominant discourse amongst healthcare professionals presumes that people on haemodialysis, and particularly those on home-based therapies can manage their treatment autonomously. While most of the participants in the study affirmed their autonomous, self-management of the treatment regime, their dependence on medical technology always undermined their sense of autonomy.

Correspondingly, the participants in the study by Hagren et al (2001) expressed the importance of being able to achieve a sense of personal autonomy in the management of ESRD and dialysis therapy. However, the participants' dependence on the dialysis machine, and the healthcare providers undermined their sense of autonomy. They

interpreted haemodialysis as a lifeline and were acutely aware that their lives depended on the treatment.

The more recent study by Hagren et al (2005) subsequently highlighted the participants' determination to manage their lives on haemodialysis therapy as autonomously as possible. However, the vulnerability experienced by the participants because of their dependence on both the healthcare providers and the dialysis machine, diminished their sense of autonomy.

Similar findings were reported in a study by Giles (2005), which explored the life-world of three people on home-haemodialysis therapy. Like the previous study by Giles (2003), a psychological approach to phenomenology based on the work of Van Manen (1997) was employed. Semi-structured interviews were carried out with the participants and data were analysed using an approach by Van Manen (1997). The participants' accounts conveyed a paradoxical struggle between dependence and autonomy. Although the participants performed the treatment independently at home, their dependence on the dialysis machine limited their capacity to act as wholly autonomous agents.

2.7 SUMMARY OF THE LITERATURE REVIEW

This literature review highlighted that the person's experience of ESRD on haemodialysis was predominantly based on an empirical psychological framework.

This research largely relied on quantitative approaches to measure and quantify various elements of the person's experience using questionnaires. Most of these questionnaires adapted a structured and closed-ended approach, which limited the responses of the participants. As a result, an in-depth, detailed account of the person's experience was not achieved.

While there were a number of qualitative research studies, which explored the individual's experience of ESRD, these studies were also primarily grounded within a psychological framework. Hence, they adapted psychological concepts and theories to explore the person's subjective experience of ESRD and dialysis. Nonetheless, this

literature provided some interesting and insightful contextual information on the person's experience of ESRD.

For instance, the literature emphasised suffering as a predominant issue within the subjective experience of chronic illness. There were various factors associated with suffering, represented in the literature related to the person's experience of ESRD. The distressing physiological symptoms, and the losses and lifestyle disruptions incurred by the disease, were described as a profound source of suffering. For some individuals, the combined impact of these issues culminated in a loss of self. The loss of self was also identified as a fundamental source of suffering, which initiated distressing emotional responses within the individual.

In particular, the distressing emotions of uncertainty and anxiety were most prevalent in the existing qualitative literature related to the person's experience of ESRD and dialysis therapy. It seemed that many individuals used strategies to suppress their uncertainty and anxiety, in an effort to prevent themselves being overwhelmed by these distressing responses. Consequently, they experienced a dynamic movement between the release and suppression of anxiety and uncertainty.

These oscillatory characteristics mirrored certain features of the model of suffering, advanced by Morse (2001). According to Morse (2001), people moved back and forth between the suppression and release of distressing emotional responses, until they were ready to accept their loss, and progress out of suffering. The experience of hope played a specifically important role in this progression, as it enabled the person to move beyond suffering and onto the reformulated self.

The notion of reformulating the self was contained within the existing literature that pertained to the person's experience of ESRD. However, it was more commonly conveyed as a process of transformation. Transformation was portrayed as an essential feature of adjustment or adaptation to ESRD and dialysis. It involved a process where the self was re-structured and re-defined. The process of transformation facilitated individuals to develop a new sense of normality.

As this brief summary of the literature review has illustrated, the qualitative literature provided more depth and detailed information about the person's experience of ESRD and dialysis. In particular, the work of Morse and colleagues on the concept of suffering provided a useful framework to describe the findings of this literature. However, it is important to note that this research primarily originated from a psychological perspective, where the predominant focus was on the person's subjective or cognitive experience of illness.

2.8 JUSTIFICATION FOR THE STUDY

Like the existing quantitative literature, the Cartesian dualistic world-view of the person was entrenched within the qualitative research related to the person's experience of ESRD and dialysis. In other words, the emphasis on the perspective of the self as "subject" and the world as "object" formed its basis. As a result of this Cartesian view of the self, the existing qualitative research tended to explore the person's experience of illness in terms of psychologically or cognitively based concepts, theories, emotions and attributes. This does not suggest that there was anything inherently wrong with this research. Rather, it is proposed that this research predominantly understood and interpreted the self cognitively or psychologically as subject.

By repeatedly interpreting the self in this manner, it is suggested that this research may have effectively concealed, or covered over other equally valuable interpretations of the person and his/her experience of ESRD and dialysis. Therefore, there is a need to provide an alternative approach to explore the person's experience, which would overcome the subject/object dichotomy retained in the existing literature.

In an effort to overcome this Cartesian dualistic perspective, this research study proposes an alternative way to explore the person's experience of ESRD and dialysis. In particular, it is suggested that the use of a hermeneutical phenomenological methodology, based on the philosophy of Martin Heidegger will provide this alternative perspective.

Heidegger's radical philosophy moves away from the dualistic thinking of Descartes, and offers a radicalised approach to understanding the human, as being-in-the-world. Heidegger's interpretation of the human being challenges the psychological view of the self that we have adapted from Descartes (Aho, 2007). Heidegger suggests that the human being does not merely consist of a material body (object) separated from an immaterial mind (subject). Rather, from Heidegger's (1962) point of view, the self cannot be properly understood in terms of its objective properties, but in terms of what it does, "proximally and for the most part-in its average everydayness" (p16). Consequently, Aho (2007) insists that Heidegger's philosophy illustrates how psychology continues to "misinterpret the self as either a masterful, subjective consciousness or a quantifiable, causally determined object" (p37).

According to Heidegger, the world is not a container filled with objects, which is cut off and separated from the self. Rather the self is embedded within the meaningful nexus of social relations, which constitute the world (Aho, 2007). As Heidegger (1982) points out:

Self and world belong together in the single entity, the Dasein. Self and world are not two beings, like subject and object, or like I and thou, but self and world are the basic determination of the Dasein itself in the unity of the structure of being-in-the-world (p318)

This phenomenological perspective of the self challenges the philosophical assumptions of the Cartesian world-view and provides an alternative way to interpret what it means to be a human being. Indeed, Benner (1994) suggests that it was Heidegger's shift from considering problems of epistemology (the study of the nature of knowledge) to considering the problem of ontology (the study of what it means to be a human being) that radically altered modern debates on the nature of science and of knowledge. The author continues to suggest that nursing could benefit from considering the ontological question of what it is to be a person, prior to considering the epistemological questions, which tend to feature in much of the nursing literature.

Therefore, the methodology selected to achieve the aim and objectives of this study is hermeneutical phenomenology. In particular, the methodology is predominantly informed by the philosophy of Martin Heidegger. It is proposed that this methodology provides an alternative approach to explore the experience of the person with ESRD on

haemodialysis therapy than is currently provided in the existing literature. However, Leonard (1994) contends that it is critical to consider the Heideggerian notion of the person prior to considering any notions of hermeneutical phenomenology as a research methodology.

In particular, the notion of time or temporality forms the basis of Heidegger's interpretation of the human being. While a small number of studies have used a Heideggerian phenomenological approach to explore the person's experience of ESRD (Rittman et al., 1993; Sloan, 1996; Sloan, 2002), these studies do not accentuate Heidegger's perspective of time. Conversely, Heidegger's (1962) analysis of time specifically provides the philosophical perspective for this hermeneutical phenomenological study into the experience of the person with ESRD on haemodialysis therapy. This philosophical perspective also provides the background to the sampling strategy, techniques for data collection and analysis, and the interpretation and discussion of the findings. These issues will be discussed in detail in the upcoming research methodology chapter.

CHAPTER 3 : RESEARCH METHODOLOGY

The methodology employed within this study is hermeneutical phenomenology. This chapter provides a detailed discussion of all aspects of the research methodology. It explains the objectives of the study, the philosophical perspective of the study, the sample and setting, the methods of data collection and analysis, the strategies to ensure the rigor of the study, and ethical issues.

3.1 AIM AND OBJECTIVES OF THE STUDY

The overall aim of this study was to provide an accurate, detailed, and in-depth description of the person's experience of ESRD and haemodialysis therapy. The specific objectives of the study were to explore the experiences of ESRD and haemodialysis therapy in a sample of adult renal patients who:

- I. Were at various stages of the lifecycle.
- II. Had been on haemodialysis therapy for various lengths of time.
- III. Were on the waiting list for a kidney transplant.
- IV. Were not on the waiting list for a kidney transplant.
- V. Had previously received a kidney transplant.
- VI. Had not previously received a kidney transplant.

3.2 PHILOSOPHICAL PERSPECTIVE OF THE STUDY

The approach to hermeneutical phenomenology in the study is specifically informed by the philosophy of Martin Heidegger (1889-1976). Although Edmund Husserl (1859-1938) founded the phenomenological movement, his approach to phenomenology is different to that of Heidegger. Therefore, I will begin by outlining some aspects of phenomenology from Husserl's perspective in an effort to highlight these differences.

Through phenomenology, Husserl sets out to advance the philosophy of the time, which was founded on the tradition of Descartes.¹⁴ Husserl challenges the Cartesian dualistic perspective with his approach to phenomenology. Husserl views philosophy as a rigorous science, which is specifically related to consciousness (Johnson, 2000; Crowell, 2005). Therefore, his approach to phenomenology involves an investigation into consciousness.

According to Husserl, we are conscious beings who always inhabit an experiential world, which he calls the “life-world” (*Lebenswelt*) (Moran, 2000, 2005). The life-world provides the foundation for all our everyday living and activities (Moran, 2000, 2005). It is always already there, and all our experience takes place within its horizon (Moran, 2000, 2005). From Husserl’s perspective, consciousness plays a primary role in displaying the life-world of the individual (Moran, 2000, 2005). Husserl wants to bring to light our experiences of the life-world, or our lived experiences as they appear through the ultimate structures or “essences” of consciousness (Koch, 1995). He believes that this is achieved through intentionality. Consequently, Moran (2005) implies that for Husserl, intentionality is “the fundamental characteristic of conscious, mental, or psychic life” (p54). It provides the backdrop to his work on phenomenology.

Intentionality in phenomenology does not mean the purpose we have in mind when we act (e.g. I intend to go shopping). Intentionality applies primarily to the theory of knowledge (epistemology) and is not related to practical activity (Sokolowski, 2000). Intentionality implies that all consciousness is consciousness “of” something, or an experience “of” something (Sokolowski, 2000). In other words, any act of consciousness is directed toward an object of some kind. Husserl uses the term *noema* to describe the objects in the world, which are intended (e.g. an object, a person), and the term *noesis* to describe the intentional or cognitive acts by which we intend things (e.g. perception, imagination) (Sokolowski, 2000). Intentionality provides a channel between consciousness and the objects in the world. In this way, Husserl believes that his notion of intentionality overcomes the subject-object dichotomy inherent in the Cartesian philosophy.

¹⁴ See pages 18-19 for the previous discussion on Descartes and Cartesian dualism.

To discover consciousness, one must adopt a phenomenological attitude, which Husserl describes as *phenomenological reduction* (Sokolowski, 2000). In order to achieve this reduction and reach the essence or ultimate structures of pure consciousness, we must suspend our intentionalities (Sokolowski, 2000). This requires us to suspend our beliefs or *bracket* out the world and all the things in it (Sokolowski, 2000). This includes the world as perceived by the individual in everyday life, and as interpreted by philosophers and scientists (Koch, 1995). Once we have successfully performed this process of suspension or phenomenological reduction, we will discover and be able to describe the essence of consciousness. The notion of phenomenological reduction or bracketing is embedded within the research, which explores the person's experience of ESRD using a Husserlian or psychological approach to phenomenology (White & Grenyer, 1999; King et al., 2002; Giles, 2003; Heiwe, Clyne & Dahlgren, 2003).

However, Heidegger (1962) disagrees that Husserl's approach to phenomenology overcomes the dualistic thinking of Descartes. Instead, Heidegger signifies that the problem with Husserl's phenomenology is that it is embedded in the Cartesian tradition (Crowell, 2005). This is signified when Husserl makes consciousness the prominent focus of his work (Crowell, 2005). By making lived experience an "inner" or "subjective" event based on the psychological subject, Heidegger believes that Husserl has not effectively advanced the Cartesian thinking of the time. Rather the Cartesian dichotomy is inherently retained within his work. Therefore, Heidegger (1962) sets about formulating an account of human life to overcome Husserl's predominantly cognitive approach to the experiences of the human being.

Unlike Husserl, Heidegger does not view the world as separate from the human being. Instead, Lafont (2005) contends that he considers it as a "holistically structured web of significance" in which human beings live (p266). Consequently, Heidegger (1962) uses the term *Dasein*, to describe a human being. *Dasein* means "to exist" or "to be there". The use of this term reflects Heidegger's perspective of the person as "being-in-the-world" and dwelling in it. By viewing the human being in this way, Heidegger disregards the subject/object dichotomy, which still prevails in Husserlian phenomenology. He also radically shifts the focus of the philosophy of the time from epistemology (study of the nature of knowledge) to ontology (the nature of being).

Heidegger (1962) believes that we are self-interpreting beings, and this interpretation is based on background understandings, which stem from our embeddedness in the world. Interpretation makes our understanding of the world explicit through language or discourse (Palmer, 1969). For this reason, Heidegger combines phenomenology with hermeneutics. Phenomenology is derived from the Greek words *phainomenon*, which means, “that which shows itself”, and *logos*, which means discourse or language (Moran, 2000). Hermeneutics is derived from the Greek word *hermēneia*. Hermēneia originated with the Greek god Hermes who translated what is beyond human understanding into messages humans can understand (Palmer, 1969). Therefore, hermeneutics is known as a process of understanding through interpretation.

Historically, hermeneutics is described as the art or theory of interpretation of texts, and is prevalent in disciplines such as theology and law (Diekelmann, Allen & Tanner, 1989). However, Heidegger uses hermeneutics as a way to uncover the structures of being. This move not only alters the existing approach to phenomenology, it also alters hermeneutics from the interpretation of texts to the interpretation of being (Palmer, 1969). Heidegger’s (1962) notion of time is central to his understanding of being, and is subsequently central to hermeneutic phenomenology. In the second Division of *Being and Time* (after section 64), Heidegger re-describes the fundamental structures of Dasein’s being in relation to time or temporality. The purpose of this analysis is to illuminate how being can only be understood in terms of time.

As mentioned previously, a small number of studies explore the person’s experience of ESRD using a hermeneutical phenomenological approach based on the work of Heidegger (Rittman et al., 1993; Sloan, 1996; Sloan, 2002). However, these studies do not emphasise the temporal perspective, which forms the basis of Heidegger’s philosophy of the human being.

Heidegger’s (1962) notion of time or temporality provides the philosophical perspective for this hermeneutical phenomenological study into the experience of the person with ESRD on haemodialysis therapy. Therefore, his perspective of time will now be discussed in detail.

3.2.1 HEIDEGGER'S PERSPECTIVE OF TIME

According to Heidegger (1962), time does not signify our common understanding of time as objective or clock time. Instead, he uses the term ordinary time to describe the irreversible, infinite sequence of “nows”, which we understand as clock time. Heidegger (1982) indicates that our understanding of time as ordinary time emanates from the work of Aristotle.

Aristotle provides both a theoretical and experiential account of time (Lear, 1988). From a theoretical perspective, Aristotle describes time as an objective entity, which is related to space. In other words, time is related to the measurement of change or motion (Adam, 2004). Thus, time is the irreversible, infinite succession of “nows” used to measure motion or change (Lear, 1988; Crocker, 1997). Therefore, in the Aristotelian notion of time, time flows through a sequence of “nows” from the future to the past (Heidegger, 1982). This sequence includes the “now” (present), the “not-yet-now” (future) and the “no-longer-now” (past) (Chanter, 2000). However, the present “now” is the most significant in this perspective of time, because this is the segment of time in which the change or motion occurs (Crocker, 1997).

Aristotle's description of time also refers to how time is experienced. He suggests that our ability to understand the objective nature of time is based on our apprehension or experience of it (Lear, 1988). Aristotle insists that only the soul can count, thus it is the soul, which experiences change (Lear, 1988; Adam, 2004). For Aristotle, the soul possesses conscious experience (Blackburn, 1994).¹⁵ Therefore, from Aristotle's perspective, any account of the objective reality of time must include the influence of the soul (Lear, 1988).

Subsequent philosophers critique Aristotle's interpretation of time for giving precedence to the objective properties of time e.g. Husserl, Bergson. This objective perspective of time is embedded in the studies, which highlighted the time consuming nature of dialysis therapy, as a concern for patients with ESRD. Therefore, in an effort to overcome this shortcoming, these philosophers emphasise the need to give

¹⁵ However, modern philosophy of the mind dismantled this view and made it implausible to think in terms of the soul (Blackburn, 2004).

precedence to the conscious experience of time (Crocker, 1997). By doing this, they anticipate that the predominant understanding of time, as an objective entity related to space and motion is limited, thus allowing the conscious experience of time to be articulated in more detail.

However, as Heidegger points out, this development in philosophical thinking creates a situation where time is understood on the basis of the subject's conscious perception of time (Crocker, 1997). As a result, Heidegger insists this perspective of time is firmly grounded in Cartesian dualism. Moreover, the objective interpretation of time, which these philosophers are supposedly trying to overcome, is inherently contained within their descriptions of the conscious experience of time. This is clearly expressed in their predominant perspective of time as a linear, succession of "nows", which are placed "alongside" each other, but not "connected" with one another (Crocker, 1997). From this perspective, the "now" (present), the "not-yet-now" (future), and the "no-longer-now" (past) are separated by an interval (Chanter, 2000).

According to Heidegger, the only way we can interpret time from this perspective is if we understand time to be inextricably linked with space i.e. the objective perspective of time, advanced by Aristotle. Space enables us to place intervals between things and distinguish limits (Crocker, 1997). However, as Crocker points out: "Time properly conceived is duration. In duration, preceding and succeeding states are not separated from one another" (p408).

This conscious or cognitive perception of time, to which Heidegger refers, is retained in the existing research related to the person's experience of ESRD and dialysis therapy. This research highlights how the time-consuming nature of dialysis therapy causes the person to lose time when they attend the treatment (Kierans, 2005; Heiwe, Clyne & Dahlgren, 2003; Hagren et al., 2001, 2005; Polaschek, 2000). Indeed, the study by Kierans (2005) highlights how some people drive at high speeds to and from the dialysis unit in an effort to retrieve some additional hours and minutes. Within these studies, the time lost when the person attends dialysis therapy refers to the cognitive or conscious perception of time. This cognitive perspective of time is also embedded in the concept of enduring, advanced by Morse (2001). According to Morse (2001), when the person is enduring, s/he cognitively focuses on the present. By focusing on the present,

the past (i.e. cognitively remembered past) and future (cognitively imagined future) are blocked out.

However, Heidegger emphasises that our predominantly cognitive interpretation of time emanates from a superficial interpretation of the Aristotelian notion of time. He indicates that the Aristotelian interpretation of time does signify a connection between the “now”, the “not-yet-now”, and the “no-longer-now”. However, this feature of Aristotle’s work has been missed in every subsequent account of time throughout the history of philosophy (Heidegger, 1962). As a result, these subsequent accounts of time fail to advance or develop Aristotle’s interpretation of time.

For Aristotle, time is the measurement of motion, which is experienced with respect to “before” and “after” (Crocker, 1997). Aristotle uses the terms *proteron* and *husteron* to describe the before and after of motion (Crocker, 1997). However, these terms may also be translated as “earlier” or “later” (Crocker, 1997). According to Heidegger, earlier and later correspond to the objective, theoretical notion of time as an irreversible sequence of “nows”. They are temporal determinants, which describe linear points of time separated by intervals (Crocker, 1997). In contrast, Heidegger suggests that the terms “before” and “after” do not provide this perspective of time. Instead, the terms before and after signify that there is a connection between the sequence of “nows”. It suggests that there is a nexus between the present (now), the past (no-longer-now), and the future (not-yet-now) (Crocker, 1997).

Heidegger (1982) implies that every account of time since Aristotle, has interpreted the terms *proteron* and *husteron* to mean earlier and later. Hence, these accounts provide a theoretical, objective account of time in isolation of the experiential account of time, advanced by Aristotle. Heidegger insists that if we are to recognise the accuracy of the Aristotelian definition of time, we should interpret the terms *proteron* and *husteron* to mean both before and after, and earlier and later (Crocker, 1997). When we understand these terms in this way, we can see that time does not merely consist of an irreversible, infinite sequence of “nows”, nor does it consist of a separate past, present, and future. Instead, there is a connection between these dimensions of time.

Heidegger insists that by misinterpreting the ontological features, which existed in Aristotle's account of time, subsequent philosophers describe only our consciousness of time (Crocker, 1997). The shortcoming of these thinkers is that they fail to see the relationship between being and time. By re-interpreting Aristotle's account of time in this manner, Heidegger (1962) paves the way for his ontological account of time.

According to Heidegger (1962) time is *originary temporality*, and is a basic structure of Dasein's being. Therefore, in trying to understand being, we must acknowledge that it is inherently linked to originary temporality, as Heidegger (1962) points out:

Thus the way in which Being and its modes and characteristics have their meaning determined primordially in terms of time, is what we shall call its "*Temporal*" determinateness. Thus the fundamental ontological task of Interpreting Being as such includes working out the *Temporality of Being*. In the exposition of the problem of Temporality the question of the meaning of Being will first be concretely answered (p40).

From Heidegger's (1962) perspective, originary temporality forms the basis of all other modes of time. In particular, he distinguishes two additional modes of time called *world-time* and *ordinary time*. These two modes of time are a modified version of originary temporality (Heidegger, 1962; Blattner, 1999, 2005). This means that the conceptual features, which constitute originary temporality, determine the features that make up world-time and ordinary time. The following discussion will provide a detailed description of the three modes of time, beginning with originary temporality.

3.2.1.1 *Originary Temporality*

Originary temporality consists of an *ecstatic* unity consisting of the future, past, and present. *Ekstases* is the term used by Heidegger to describe how the temporal perspective of time stands out from the normal perspective of time, as objective or clock time (Gelven, 1989). He uses this term to signify, that from a temporal perspective, the present incorporates the past, and the future (Dostal, 1993).

Heidegger (1962) says that Dasein's being consists of three elements: *existence*, *facticity*, and *falling*. These three elements together are called the *care-structure* and each of the elements is grounded in an ecstases of originary temporality (Blattner, 1999,

2005). Therefore, existence, facticity, and falling, are grounded in the future, past, and present respectively. Heidegger (1962) implies that the care-structure of Dasein needs to be disclosed in an effort to understand being. *Disclosedness* means to allow the care-structure to be seen, or make it manifest (Blattner, 1999, 2005). Heidegger identifies four constituent elements of disclosedness including *understanding*, *affectedness*, *fallenness*, and *discourse* (Blattner, 1999, 2005). The three ecstases of originary temporality will now be discussed in relation to the three elements of the care-structure and three elements of disclosedness. Discourse discloses the temporally situated care-structure of Dasein's being through language. Consequently, this constituent element of disclosedness will be addressed separately after the following discussion on time.

3.2.1.1.1 The Originary Future

Existence is grounded in the originary future and is disclosed through understanding. Understanding is the ability to grasp one's possibilities for being, within the context of his/her world (Palmer, 1969). Dasein understands itself by pressing ahead or projecting itself forward into some way of life, or some possibility of being (Gelven, 1989; Mulhall, 1996; Blattner, 1999). As Heidegger (1962) conveys: "understanding projects the being of Dasein...Dasein understands itself - it always has and always will - in terms of possibilities" (p145)

This projection or "pressing-ahead" exemplifies that understanding is related to the future. However, the future from Heidegger's (1962) perspective does not correspond with the ordinary conception of the future in terms of a sequence of "nows". It does not signify a "not yet now-but later" (Heidegger, 1962; p375). Rather, Dasein is futural in that it understands itself by projecting itself forward into some way of life, or some possibility of being (Palmer, 1969).

This way to be Dasein is not something that will come later and thus belongs to the future (Mulhall, 1996; Blattner, 2005). My possibilities are not something that can become an end-state, but instead are something, which I continuously go towards. For example, if I understand myself as a nurse, I will project myself forward in a nurse's way of life. Hence, understanding myself as a nurse does not end when I complete the programme of training to become a nurse. Being a nurse is something I continuously

cast myself as, it is always futural in terms of what I am doing now. Heidegger (1962) states:

By the term 'futural', we do not here have in view a "now" which has *not yet* become 'actual' and which sometime *will be* for the first time. We have in view the coming in which Dasein, in its ownmost potentiality-for-Being, comes towards itself (p373).

From this perspective, my future possibilities are more extensive than the goals I can achieve in the future. What I can "be" in the future is something which will never be complete, and is therefore something that I continuously cast myself toward (Blattner, 1992). Therefore, Dasein is never ultimately finished, because there are always possibilities, always a "not-yet" that shows up as mattering (Blattner, 1992). This gives it a sense of purpose and anticipation.

According to Palmer (1969), the projection associated with understanding must have a base. Therefore, understanding is always related to *facticity*.

3.2.1.1.2 The Originary Past

Facticity is grounded in Dasein's originary past. Heidegger (1962) describes facticity as the basis (*Grund*) of existence. By factual existence, he means the worldly involvement of the human being in the world. For Heidegger, the world is the significant set of relationships, practices, and language that we have by virtue of being born into a particular culture (Leonard, 1994). He uses the term *thrownness*, to express a feature of factual existence, which implies that Dasein is always already in a situation. Thus, thrownness signifies that we are cast into certain circumstances, and subsequently live out our possibilities in life in terms of this thrownness (Wrathall, 2006). Thrownness provides the basis or the ground for our projected possibilities (Blattner, 1999). Heidegger's (1962) notion of thrownness is based on the conceptions of *affectedness* and *attunedness*.

Affectedness (*Befindlichkeit*) discloses Dasein in its thrownness. Affectedness can be described as the way things show up as mattering to us, or the way we are affected by things. Affectedness is based on the interpretation of moods (*Stimmung*) (Dreyfus, 1991). Attunedness is the term used by Heidegger to describe the interpretation of

moods (Dreyfus, 1991). Our attunedness highlights the different ways that things show up as mattering to us (Heidegger, 1962). These attunements are not past events but instead belong to the past ekstases of originary temporality, which Heidegger describes as *beenness* (*Gewesenheit*). Heidegger uses the term beenness to highlight that the past, experienced as the historicity of Dasein, is not bygone (Inwood, 1997). It is something I can return to again and again-it is a living past. Heidegger (1962) claims that “as long as Dasein factually exists, it is never past [vergangen], but it always is indeed as already having *been*, in the sense of the ‘I *am-as-having-been*’ ” (p376).

In other words, Dasein is historical because it is thrown into the world and has acquired an understanding of being from its past tradition. Because Dasein is thrown into the world, *being-with-others* is an essential structure of its existence. Dasein is thrown into the world along with others. Therefore, being in the world is social in nature (Heidegger, 1962).

This temporal account of the past as *having-been* is different from the ordinary perspective of the past as a pure “now”, which has passed away to become a “no-longer-now”. Dasein’s possibilities matter to it because of its affectedness and attunements from the past. The past sets up the possibilities for Dasein’s future existence. For example, if I am attuned to caring or if caring matters to me, I may become a nurse. That is, I press ahead into being a nurse because it is important to me. If this possibility did not matter to me, I would not pursue it. In fact, it is because these possibilities matter to me that I act in a specific way in the originary present.

3.2.1.1.3 The Originary Present

The present ekstases of originary temporality is significant in relation to being because Dasein performs every action in the present “in-order-to” project forward into some goal or possibility in the future. As Heidegger (1962) points out, “The horizontal schema for the *Present* is defined by the ‘*in-order-to*’ ” (p416). Blattner (1992) suggests that it is the present, which highlights the spannedness of originary temporality, described by Heidegger. We act in the present, based on our attunements from the past, to project forward into possibilities in the originary future (Blattner, 1992). Consequently,

temporality is not three separate dimensions of time, rather it is a unified whole, with a projective or purposeful character based on the originary future (Blattner, 1992).

According to Heidegger (1962), our ordinary life causes us to fall away or become submerged in forms of complacency and everydayness. Therefore, the everyday manner in which we live is characterised by *falling* (*Verfallen*) (Moran, 2000). Falling consists of our everyday tasks, activities and involvements in the world. In falling, we merely pass information along and allow ourselves to be absorbed in idle talk and gossip. We are simply the same as everybody else; we are in the state of “*Das Man*” (Heidegger, 1962).

Falling is grounded in the present ecstases of originary temporality (Dostal, 1993; Blattner, 1999, 2005). Therefore, Heidegger (1962) describes the originary present as world-time because falling refers to Dasein’s everyday involvements in the world. World-time originates out of the originary present, and subsequently retains some of the conceptual features of originary temporality (Blattner, 2005).

3.2.1.2 World-Time

World-time is the second mode of time described by Heidegger (Blattner, 2005). It is the irreversible sequence of times called “nows”, where the present is the “now”, the past is the “no-longer-now” and the future is the “not-yet-now”. The term world-time is used to describe this mode of time because it is the time that relates to falling. Therefore, world-time is Dasein’s qualitative experience of time in its everyday involvements in the world (Blattner, 2005). In particular, it is the time that contains the everyday activities performed by Dasein.

As previously mentioned, world-time is constituted by the present ecstases of originary temporality. Therefore, the structure of world-time originates out of, and is simultaneously embedded within originary temporality through the originary present (Heidegger, 1962; Blattner, 2005). Indeed, Blattner (2005, p319) describes world-time as a “levelled-off” or “thinned out” version of originary temporality. This means that

world-time is part of the unified structure of originary temporality, and subsequently forms the basis for the care-structure of Dasein's being.

Like originary temporality, the world-time "now" (present) also consists of a past (no-longer-now) and a future (not-yet-now). However, the past, present, and future of world-time, relate specifically to Dasein's use of equipment and tools in its everyday involvement with the world. Heidegger (1962) describes Dasein's practical use of tools and equipment in its everyday tasks, as the *temporality of circumspective concern*. He states that the temporality of circumspective concern is grounded or embedded in world-time. Moreover, certain characteristics of world-time are indirectly derived from originary temporality, by way of the temporality of circumspective concern (Blattner, 1999).

Heidegger (1962) indicates that it is our ability to project into the originary future, which structures the temporality of circumspective concern. Therefore, the projective character of the future of originary temporality provides the basis for the everyday activities and tasks performed in world-time by Dasein. In other words, we engage with tools and equipment in the temporality of circumspective concern "in-order-to" project forward into goals and possibilities in the originary future.

Remember that in originary temporality, every action is performed in the present "in-order-to" project forward into some possibility in the future. Therefore, the projective character of the future of originary temporality provides the projective character for the temporality of circumspective concern.

There are two characteristics of the temporality of circumspective concern called *awaiting* and *retaining* (Heidegger, 1962). Through world-time, these characteristics constitute the actual activity of the originary present (Gelven, 1989). Therefore, the projection of originary temporality is preserved in these characteristics. Awaiting refers to the way Dasein looks forward or anticipates the completion of the task. Heidegger (1962) indicates that when Dasein uses equipment or tools, it awaits or expects the completion of the task. Retaining refers to Dasein's manipulation of the tools and equipment in the completion of the task (Blattner, 1992). Dasein retains a background

of practical experience, which informs its use of equipment and tools (Gelven, 1989). Heidegger calls this background experience the *wherewithal*.

Therefore, when confronted with a task, Dasein retains the wherewithal or background experience to complete the task. By retaining or relying on this wherewithal, Dasein is able to select and use the most appropriate tools and equipment to get the task done. The temporality of circumspective concern involves Dasein both awaiting the completion of the task, and retaining the wherewithal required to complete the task. It is the feature of world-time, which constitutes the actual activity of the originary present (Gelven, 1989).

As previously mentioned, it is the projective character of the originary future, which structures the temporality of circumspective concern (Blattner, 1999). However, this feature only becomes apparent when the tools or equipment we use in our everyday tasks break down. The tools and equipment, which Dasein uses to perform everyday tasks becomes inconspicuous (Palmer, 1969). These objects are so taken-for-granted by Dasein that they take on a bodily presence (Blattner, 2005). Heidegger (1962) uses the term *readiness-to-hand* or *availableness* to describe the smooth and transparent functioning of the equipment and tools, which Dasein uses in its everyday practical activities. Indeed, he indicates that it is only when the equipment cannot function as ready-to-hand, such as in breakdown, that these tools/equipment become visible.

At the point of breakdown, the significance of the tool or piece of equipment is highlighted (Palmer, 1969). In other words, the tool/ equipment is viewed as something to be wielded “in-order-to” bring some goal to realisation in the future (Mulhall, 1996; Blattner, 2005). Thus, it is only when some breakdown in the equipment or tools occur that the existential significance of the temporality of circumspective concern is highlighted (Mulhall, 1996; Blattner, 2005). In breakdown, the “in-order-to” function of the tool or piece of equipment is revealed.

It is the purposeful character of the temporality of circumspective concern, which gives world-time its sequential and irreversible characteristics. World-time is sequential and irreversible because the future has priority in originary temporality (Blattner, 2005). Dasein’s continual progression in one direction toward the future creates a string or

sequence of tasks, with each task leading to a subsequent task (Blattner, 2005). Therefore, world time is irreversible and sequential because it structures Dasein's use of the equipment and tools in its everyday practical activities.

The above discussion highlights that world-time is derived indirectly from originary temporality, via the temporality of circumspective concern. However, there are specific features of world time itself, which depend explanatorily upon originary temporality (Blattner, 1999). Heidegger (1962) identifies these four features as *significance*, *datability*, *spannedness*, and *publicness*. Each of these features can be seen as a modified version of some feature of originary temporality (Blattner, 2005). The following discussion will analyse the four features of world-time and their correspondence with originary temporality.

3.2.1.2.1 Significance

According to Heidegger, world-time is significant because the “now” is always understood by Dasein as either the right time or wrong time to do certain things (Blattner, 1999, 2005). Therefore, the “nows” of world-time are significant because they are either appropriate or inappropriate for certain activities. The significance of world-time is always based on the future of originary temporality. I perform certain tasks in world-time “in-order-to” project forward into possibilities in the future. Therefore, it is ultimately these possibilities that determine whether it is the right or wrong time to perform certain activities.

3.2.1.2.2 Datability

Datability implies that the experience of time is dated by events. Therefore, Dasein's experience of the “now” of world-time is experienced as a time when a significant event occurs e.g. dinnertime, time to read, time to use the computer (Blattner, 1999). This perspective of time is different to our view of time as an objective, linear succession of empty “nows”. World-time does not refer to the clock time of seconds, minutes or hours. Instead, world-time relates to Dasein's everyday engagement in the world. It refers to times, which have a qualitative content i.e. as times when something

significant happens (Blattner, 2005). Dasein dates events in its everyday involvement in the world because the events have significance (Blattner, 2005). As mentioned above, this significance is based on the purposeful character of the originary future.

3.2.1.2.3 Spannedness

World-time is spanned because it is embedded in the originary present (Gelven, 1989; Blattner, 1999). The originary present spans from the originary future to the originary past. Therefore, this spannedness is retained in world-time. The spannedness of world-time is illuminated in the temporality of circumspective concern. Remember in the temporality of circumspective concern, Dasein performs tasks in the “now”, by retaining the necessary background experience (wherewithal), and awaiting the completion of the task. Therefore, the “now” of world-time extends or spans from the “not-yet-now” to the “no-longer-now”. As a result of the spannedness of world-time, every “now” lasts for a while (Blattner, 1999, 2005). For example, the “now” while I type on my computer lasts from a before, when I was walking to the computer, to an after, when I go to lunch.

3.2.1.2.4 Publicness

The “now” of world-time is public. This means that we collectively understand what “now” means (Blattner, 1999, 2005). The publicness of the “now” of world-time ensures that we are able to collectively coordinate our tasks, activities, and practices on a daily basis (Blattner, 1999, 2005). The coordination of activities through the publicness of world-time ensures that a breakdown in activities is for the most part avoided. Consequently, this enables society to function smoothly and cohesively (Blattner, 1999, 2005).

According to Heidegger (1962), world-time is public because originary temporality is public. Because Dasein is thrown into the world, being-with-others is an essential structure of its existence. As originary temporality forms the basis of Dasein’s existence, then being-with-others is also a feature of originary temporality. As Heidegger (1962) states:

The 'now' which anyone expresses is always said in the publicness of Being-in-the-world with one another. Thus the time which any Dasein has currently interpreted and expressed has as such already been *given a public character* on the basis of that Dasein's ecstatical Being-in-the-world (p463-464).

Heidegger continues to suggest that all of the projects, which Dasein aims to realise in the originary future stem from it being part of a social world (Blattner, 1999, 2005). Therefore, world-time is public because Dasein's activities are constituted by being-with-one-another (Blattner, 1999, 2005).

To summarise, world-time is the irreversible sequence of times called "nows". It is the time that relates to falling i.e. Dasein's experience of time in its everyday involvements and activities in the world. Therefore, world-time originates out of the present ecstases of originary temporality, and subsequently retains some of its features. These features include significance, datability, spannedness, publicness, and sequentiality. Each of these features is a modified form of originary temporality (Blattner, 1999).

In addition, world-time consists of Dasein's use of equipment and tools in its everyday involvement with the world. Heidegger (1962) describes this as the temporality of circumspective concern. The temporality of circumspective concern has a purposeful or teleological character, which it derives through world-time, from the originary future. This purposeful character of the temporality of circumspective concern provides world-time with its sequential and irreversible flow.

3.2.1.3 Ordinary Time

According to Heidegger (1962), ordinary time is the infinite, irreversible succession of "nows", which we associate with clock time. It is viewed as the pure container of events and the medium in which change occurs (Blattner, 2005). Unlike world-time, ordinary time is deemed independent from human's involvement in the world (Blattner, 2005). Therefore, the "nows" of ordinary time are empty and do not relate to Dasein's everyday activities and tasks.

In the ordinary interpretation of time as a sequence of “nows”, world-time is levelled off. The levelling off of world time means that the datability and significance of the “now” of world-time are covered over. Heidegger (1962) claims:

In the ordinary interpretations of time as a sequence of “nows”, both datability and significance are *missing*. These two structures are *not* permitted to ‘come to the fore’ when time is characterized as a pure succession. The ordinary interpretation of time *covers them up*. When these are covered up, the ecstatico-horizonal constitution of temporality, in which the datability and the significance of the “now” are grounded, gets *levelled off*. The “nows” get shorn of these relations, as it were; and, as thus shorn, they simply range themselves along after one other so as to make up a succession (p474).

Without significance and datability, the “nows” lack the qualitative content, which is characteristic of world-time. Therefore, all we are left with is an infinite and irreversible sequence of empty “nows” (Blattner, 1999). Irreversibility and infiniteness are the conceptual features, which essentially constitute ordinary time.

3.2.1.3.1 Irreversibility

According to Heidegger, we can understand the irreversibility of ordinary time when we see it as a levelled off version of world-time (Blattner, 1999, 2005). The previous discussion on world-time, suggests that it is irreversible as a result of the purposeful character of the future of ordinary temporality. Hence, it is because of the irreversibility of world-time that ordinary time is irreversible. Blattner (1999) illustrates this stating, “the irreversibility of ordinary time is grounded in the irreversibility of world-time, which itself has to do with world-time’s contentful features and, in turn, arises from ordinary temporality” (p223).

3.2.1.3.2 Infiniteness

Heidegger (1962) suggests that when we perceive time from a theoretical and cognitive perspective, it is understood to be infinite. Heidegger (1962) uses the term *present-at-hand* to describe the theoretical and cognitive way in which we sometimes understand being-in-the-world. His account of the present-at-hand theoretical mode of cognition can be applied to his discussion on ordinary time.

From Heidegger's (1962) perspective, we can only perceive time as infinite, if we view it through the lens of the present-at-hand mode of cognition. By observing time from this objective, theoretical stance, the conceptual features, which constitute world-time, are concealed (Blattner, 2005). Instead, we focus on the endless sequence of "nows", in isolation of Dasein's practical everyday involvements in the world, as Heidegger (1962) suggests:

The principal thesis of the ordinary way of interpreting time—namely, that time is 'infinite'... This thesis becomes possible only on the basis of an orientation *towards a free-floating "in-itself" of a course of "nows" which is present-at-hand*—an orientation in which the full phenomenon of the "now" has been covered up to its datability, its worldhood, its spannedness, and its character of having a location of the same kind as Dasein's, so that it has dwindled to an unrecognizable fragment (p476).

Based on Heidegger's (1962) account, world-time forms the basis of ordinary time. We do not normally understand ordinary or clock time as an abstract, isolated entity. Instead, we understand clock time in relation to the everyday activities we perform in world-time (Blattner, 1999, 2005). Therefore, Dasein uses clock time so it can fit a number of tasks into each day (Blattner, 1999, 2005). However, if we focus primarily on the endless sequence of ordinary time, we overlook the features of world-time, which provide its basis.

When we understand ordinary time as a levelling-off of world-time, we can see that ordinary time also originates, through world-time, from originary temporality. Since originary temporality forms the basis of the care-structure of Dasein's being, Heidegger's thesis suggests that time ultimately depends upon human beings (Blattner, 1999, 2005). Hence, without Dasein there would be no time.

To summarise, originary temporality incorporates an ecstatic unity consisting of the future, past, and present. From this perspective, time is not merely the infinite, irreversible sequence of "nows", which we associate with clock time. Instead, in originary temporality, the present incorporates the past, and the future (Dostal, 1993). According to Heidegger (1962), there are two additional modes of time, which originate from originary temporality called world-time and ordinary time. The explanation of world-time and ordinary time is dependent on originary temporality because these two

modes of time are derived from originary temporality (Blattner, 1999, 2005). Moreover, the conceptual features, which constitute originary temporality, determine the conceptual features, which make up world-time and ordinary time. Consequently, originary temporality forms the basis of the other two modes of time.

According to Heidegger (1962), originary temporality is a basic structure of Dasein's being, which he refers to as the "care-structure". The care-structure consists of three elements known as existence, facticity, and falling. Each of these elements is grounded in an ecstases of originary temporality. The future corresponds with existence, the past corresponds with facticity, and the present corresponds with falling.

The care-structure of Dasein's being is disclosed through understanding, affectedness, falling, and discourse. Apart from discourse, each element of disclosedness has already been discussed. For instance, existence is disclosed through understanding, facticity is disclosed through affectedness, and fallenness is disclosed through everydayness or falling. Discourse is the fourth, and final way in which the temporally embedded care-structure of Dasein's being is disclosed, and shall now be discussed.

3.2.1.4 Discourse (Language)

Discourse is the way Dasein discloses the whole of the care-structure through language. According to Palmer (1969) this represents the hermeneutical process because it is the process where being becomes thematised by language. As mentioned already, understanding occurs within the interrelated formation of the care-structure, and it is based on originary temporality. It is this entire structure that provides the contextual basis for language, as well as the possibility that words can have significance for us at all (Palmer, 1969; Moran, 2000). However, it is through interpretation that our understanding is made explicit through language.

As a result of the contextual basis of discourse or language, when we see something, we interpret it "as" this or "as" that, based on this background understanding. Therefore, interpretation renders explicit the word "as" because prior to every statement that I make about an object, there is a foundation of understanding (Lafont, 2005). For

example, when we see a chair, we do not see it as a piece of wood, we see it “as” something to sit on, as something comfortable or uncomfortable.

Heidegger (1962) describes this interpretation as the *hermeneutical* form of the word “as” and continues to differentiate between this, and what he terms the *apophantic* form of the word “as”. The apophantic “as” refers to the logical assertions and/or theoretical statements, used by science to describe the human being. Heidegger (1962) uses the example “the hammer is heavy” to illustrate what he means by the apophantic “as”. He says that the interpretation of the hammer “as” something with physical properties, such as heaviness, is indicative of science’s approach to interpreting things based on logical assertions and theoretical statements (Palmer, 1969). From this interpretation, the hammer is described as something with objective properties, which can be observed.

According to Heidegger (1962), the “as” which interprets the hammer in an objective way, as something that can be weighed, measured, and categorised, is the apophantic “as”. However, he contests that this narrow interpretation of the hammer “as” object simultaneously conceals its function “as” a tool, which is used in our everyday involvements in the world.

In contrast to the apophantic “as”, the hermeneutical “as” interprets the hammer as something, which is used in the tasks and activities we perform everyday in world-time.¹⁶ We use these tools in world-time to perform tasks “in-order-to” project forward into possibilities in the originary future. However, when we interpret the hammer as merely an object i.e. in terms of the apophantic “as”, it is effectively severed from its temporal and existential context i.e. the hermeneutical “as” (Palmer, 1969). When we interpret the hammer in terms of the apophantic “as”, this lived, relational context is disconnected, and the hammer is presented as something to be observed in terms of theoretical characteristics and categories.

¹⁶ See page 97 for the previous discussion on world-time.

However, this detached perspective fails to acknowledge that the interpretation of the hammer in terms of the apophantic “as” is based on the hermeneutical “as” interpretation of the hammer (Palmer, 1969). In other words, our ability to assert that the hammer is too heavy is entirely based on our involved, engaged use of the hammer in everyday practices. It is only because we are unable to complete our tasks effectively that we interpret the hammer as being too heavy. At this point, the theoretical properties and characteristics of the hammer become evident. Otherwise, the hammer would not show up for us at all, because we would be using it in an absorbed, engaged manner.

Similarly, it is only by ignoring the more original hermeneutical “as” that the human being can be understood and described in terms of mere theoretical categories and constructions (Palmer, 1969). From Heidegger’s (1962) perspective, the apophantic “as” is based on the hermeneutical “as”. However, the scientific method, which values objectivity, gives primacy to interpretations of the human being, which are entirely based on the apophantic “as”.

Heidegger (2001) continues to suggest that all of the variations of modern psychology are held beneath the approach of the scientific method. As a result, the psychological interpretation of human experience and emotional suffering is predominantly interpreted from the perspective of detached objectivity, using causal interactions, categories, and theoretical constructions (Heidegger, 2001). In other words, the psychological framework interprets human experience in terms of the apophantic “as”.

If we recall, this was highlighted in the literature review on the person’s experience of ESRD and dialysis. The literature predominantly emanated from a psychological perspective, which used quantitative methodologies to examine the person’s experience in an objective manner. The findings of this research described the person’s experience in terms of predetermined characteristics, concepts, and theories. In addition, the qualitative literature was also grounded within this psychological framework and drew on psychological characteristics, concepts, and theories to explore the person’s experience of ESRD and dialysis.

The findings of this literature showed that the person's experience of ESRD and dialysis is primarily interpreted in terms of the apophantic "as" rather than the hermeneutical "as". However, as Heidegger (1962) emphasises, if we continually interpret human experience based purely on the apophantic "as", we will effectively conceal or cover over the hermeneutical "as", which forms its basis. Therefore, Heidegger (1962) stresses the need to get beyond this restricted view of the human being and delve deeper into the hermeneutical "as". His hermeneutical phenomenological approach of the person provides a way to get beyond the apophantic "as" (i.e. the scientific/psychological assertions), and disclose or bring to light the hermeneutical "as".

To acknowledge the hermeneutical "as" is to recognise that all interpretations about human experience (i.e. scientific/psychological) are derived from and rooted in existence or being (Palmer, 1969). As mentioned previously, our understanding of being-in-the-world is constituted by the three elements of the care-structure and the larger context of originary temporality.¹⁷ Therefore, when we interpret something through language, it conceals within it this foundation of understanding, which we have obtained from already being-in-the-world.

Heidegger calls this the *fore-structure* of understanding, and during interpretation this fore-structure of understanding is rendered explicit through language/discourse (Palmer, 1969; Diekelmann & Ironside, 1998; Lafont, 2005). There are three elements of the fore-structure: *fore-having*, *fore-sight*, and *fore-conception*. The fore-having refers to the prior intelligibility and background practices, which provide us with an understanding of the phenomena that we want to interpret. The fore-sight is the specific perspective from which we approach the interpretation, and is also constituted by background practices. Fore-conception describes our anticipated sense of what our interpreting will reveal (Palmer, 1969; Diekelmann & Ironside, 1998; Lafont, 2005). It is grounded in the conceptualisations and vocabulary that are at our disposal during interpretation.

¹⁷ See page 93 for the discussion on the care-structure and originary temporality.

Lafont (2005) contends that this notion of the fore-structure implies that interpretations are always grounded within the particular context, perspective, and conceptualisations of the interpreter. These three elements (i.e. fore-having, fore-sight, fore-conception) constitute the *hermeneutic circle* from which all interpretation evolves (Lafont, 2005).

Based on this perspective, both the researcher and participants engaged in research investigations, interpret their experience within this hermeneutic circle of understanding. However, this circular view of interpretation questions the traditional scientific aspiration of “objective” interpretations “without presuppositions” (Palmer, 1969; Lafont, 2005). As Heidegger (1962) points out: “An interpretation is never a presuppositionless apprehending of something presented to us” (p191).

For Heidegger, the notion that one can interpret without presuppositions is in direct contrast to the way understanding operates (Palmer, 1969). The unnoticed presuppositions of the person are present in every interpretive construction, so that there is no such thing as an “objective” and “presuppositionless” interpreter (Palmer, 1969). Consequently, researchers using hermeneutical phenomenology do not try to “bracket” their presuppositions, as Husserlian phenomenology would suggest. Instead, the researcher’s interpretations are grounded on his/her fore-structure of understanding.

The philosophical perspective of Martin Heidegger informs this hermeneutical phenomenological study of the person’s experience of ESRD and haemodialysis therapy. It guides all stages of the research process including the sampling strategy, the methods of data collection and analysis, and the interpretation and discussion of the findings. These elements of the research process will now be discussed in more detail in the following sections of this chapter.

3.3 RESEARCH SETTING AND SAMPLE

The setting for the study was a haemodialysis unit based in a large teaching hospital in the Republic of Ireland. Prior to the study, I had no connection or affiliation with the hospital, haemodialysis unit, or clinical care of the participants at the study hospital. According to Steeves (2000), one of the tenets of hermeneutic phenomenological research is to select people who will offer a picture of what it is like to make sense of their experience. Purposive sampling is a non-probability sampling strategy, which allows the researcher to select participants who are most likely to reveal the phenomena under study (Holloway & Wheeler, 1997).

It is important to point out, that prior to conducting this study for PhD, I had completed another qualitative study as part of a postgraduate nursing course. This initial study also explored the experience of ESRD and haemodialysis therapy for sixteen participants in another renal unit based in a large city hospital in the Republic of Ireland. While conducting this initial study, I was also a member of the nursing team on the dialysis unit. The findings yielded some interesting insights into the person's experience of ESRD and haemodialysis therapy and contributed to my decision to embark on the current study for PhD. However, I decided it would be beneficial to conduct the study for PhD at another location in the Republic of Ireland. I felt this might potentially allow me to develop a broader perspective of the person's experience of ESRD and haemodialysis therapy.

The purposive sample of sixteen participants selected in this initial study had yielded substantial amounts of data in relation to the participants' experience. Therefore, I decided that a purposive sample of sixteen participants was an appropriate sample size to yield a rich and in-depth description of the participants' experience in the current study for PhD.

The sample inclusion criteria consisted of participants who:

- Were aged 18+
- Were able to converse in English.
- Were diagnosed with ESRD and receiving maintenance haemodialysis therapy.
- Were receiving haemodialysis therapy from 0-1 years, 1-5 years, and 5-10 years.
- Were on the waiting list for a kidney transplant.
- Were not on the waiting list for a kidney transplant.
- Had previously received a kidney transplant.
- Had not previously received a kidney transplant.

The findings from the initial study highlighted that the inclusion of patients with specific kinds of experiences in the sample yielded a broader perspective of the experience of ESRD and haemodialysis therapy. For instance, some participants who were on haemodialysis therapy on a long-term basis seemed to provide different experiences than participants who were on the treatment for a shorter duration of time. Correspondingly, some participants who were on the waiting list for a kidney transplant seemed to depict different experiences than those who were not on the waiting list for a kidney transplant, and so forth. Therefore, it was deemed necessary to include these specific groups of patients within the study for PhD. The inclusion of this range of participants facilitated a more in-depth description of the experience of being a patient on haemodialysis to be formulated.

The participants were selected based on the assistance and information of the nursing and medical staff working on the haemodialysis unit. They identified patients who were either physically or psychologically unable to participate in the study, and these patients were not included in the study.

3.4 DATA COLLECTION

As mentioned previously, our understanding is based on the care-structure of our existence, and is embedded within the threefold structure of originary temporality. Dasein discloses this entire care-structure through language. Hence, the understanding people have of their experience is usually contained in the narratives or stories they tell (Benner, 1994; Ray, 1994; Kahn, 2000a). Qualitative interviews are a useful approach to elicit this narrative data (Benner, 1994; Ray, 1994; Kahn, 2000a).

Based on the findings of the initial study I had conducted as part of a previous postgraduate nursing programme, I decided that it would be beneficial to conduct the study for PhD using a longitudinal study design. I felt that a follow-up interview with the participants approximately one year after the first interview would allow the participants to offer more narratives and more descriptions of their experience of ESRD and haemodialysis therapy. It was anticipated that this would allow a more in-depth, detailed description of their experience to be developed. Within the follow-up interview, several participants' accounts illustrated that their experience had changed quite dramatically over time. Therefore, these changes in the participants' experience over time were incorporated into the findings.

It was my intention to conduct two interviews with each of the sixteen participants. The follow-up interview was conducted about one year after the initial interview. However, it was not possible to re-interview two of the initial sixteen participants. Sadly, one of these participants had died, and the other participant had relocated to another country for treatment. Three participants had received kidney transplants at the time of the follow-up interview. Two of these participants were interviewed in their own homes, and the third participant was interviewed at the transplant centre, when she attended an outpatient appointment.

The approach to qualitative interviewing in this study resembled a conversation with each interview lasting about an hour. In the first interview, one opening question was used, in which the participants were asked: "What is it like to live on dialysis therapy?" After the initial question, I followed up with probing questions such as, "Can you give me an example of that?" "What was that like?" "What did that mean to you?" and "Can

you describe or tell me more about... (e.g., a particular experience)?" These types of questions preserved the conversational nature of the interview. Therefore, the participants were not constrained by pointed questions, which could have limited the contextual nature of their narratives (Benner, 1994).

Essentially the same approach was used in the follow-up interview with the participants. In addition, I had developed a number of specific topics that needed to be addressed within the follow-up interview. These topics were based on the analysis of the data from the first interviews. For instance, in the first interview, several participants described their experience of waiting for a kidney transplant, wasting time, killing time, and communicating with nurses. Hence, I allocated enough time during the follow-up interview to specifically focus on these topics.

It was my intention to conduct the interviews with the participants either in their homes or in a quiet room, away from the haemodialysis unit. However, all the participants requested to have the initial interview while undergoing haemodialysis therapy. It seemed that the participants found the time during haemodialysis therapy lengthy and boring. Therefore, they gladly welcomed the opportunity to be interviewed about their experience during this time.

Interruptions and distractions have been described as major pitfalls during an interview (Morse & Field, 1996; Bryman, 2001). Since I had worked as a nurse on haemodialysis units in the past, I was aware of the distractions and noise, which could occur during the interviews with the participants on the haemodialysis unit. Nonetheless, it seemed unfair to request these patients to give up any more of their time to be interviewed about their illness and treatment. Consequently, there were various measures taken to minimise the potential noise and distractions on the haemodialysis unit during the interviews with participants.

For instance, the noisiest time on the haemodialysis unit seemed to occur between shifts, when patients were starting and finishing haemodialysis treatments. Through collaboration with nursing staff on the dialysis unit, I did not interview participants during these times. There were some areas on the dialysis unit, which were quieter and more private than others. By liaising with the nurses, I was able to negotiate that

participants were allocated to these areas for the purpose of the interviews. The curtains were pulled around to enhance privacy and avoid interruptions. While there was always the risk of machine alarms and the development of acute complications during haemodialysis therapy, these disruptions were minimal during the interviews with participants. All interviews with the participants were audio taped and transcribed verbatim. The transcripts were then checked against the tapes for accuracy prior to data analysis.

3.5 DATA ANALYSIS

The approach to data analysis was adapted from the work of Diekelmann, Allen & Tanner (1989). This approach was specifically developed by the authors for the analysis of data in studies using a Heideggerian hermeneutical research methodology.

In particular, Heidegger's (1962) perspective of interpretation formed the basis of this method of analysis. Diekelmann, Allen & Tanner, (1989) viewed interpretation to be grounded in the fore-structure of understanding.¹⁸ Hence, their hermeneutical approach to analysis emphasised that interpretation was always related to the background context, perspective, and assumptions of the researcher. All interpretations of the researcher were created within this "hermeneutic circle".

The approach to data analysis by Diekelmann, Allen & Tanner (1989) had previously been used in hermeneutical studies, which explored the person's experience of ESRD and dialysis therapy (Rittman et al., 1993; Sloan, 1996; Nagle, 1998). There were seven stages in the analysis process. All stages involved an intense process of reading, writing, thinking, and dialogue in relation to the data. The following account will delineate how these stages were incorporated in the analysis of the narrative data in my study.

¹⁸ See page 108 for the previous discussion on the fore-structure of understanding.

1. All interviews were read and re-read in their entirety to obtain an overall understanding of the data.
2. Interpretive summaries of each interview were written up, and a list of categories created with accompanying narrative data.
3. The categories were compared and contrasted between interview texts from all the participants. This allowed the shared or similar categories that recurred throughout the texts to be identified and developed into themes. All interpretations of the researcher were supported with narratives from the interview text. A database created in *Microsoft Access* was used to code, synthesise, store, and retrieve categories and themes. This database also facilitated searches across data for the categories and themes.
4. A central practice of the hermeneutical analysis process used in this study was the inclusion of other researchers in the interpretation of the data. For instance, I presented my interpretations to the two members of my PhD supervisory team, and to an expert practitioner in nephrology nursing with a PhD in this area. This process allowed vague or unclear interpretations to be clarified through dialogue, debate, and referring back to the interview text. Moreover, it served to challenge and affirm my interpretations, which assured the interpretations were warranted, and reflected the participants' experience. The presentation of themes and supporting narratives at both national and international research conferences also challenged and verified my interpretations of the data.¹⁹
5. When questions about interpretations were raised, I referred back to the original transcribed interview text, and my written interpretation of that text, to assess whether my interpretation was warranted. I also extended my descriptions of the interpretations to make them more comprehensive and clear.
6. As the themes were developed, refined, and compared, a constitutive pattern that linked the themes was identified.²⁰
7. A draft report of the interpretive analysis was developed and presented to the members of my PhD supervisory team. It provided a detailed discussion on the constitutive pattern and relational themes formulated from the data. The themes were supplemented with many narratives taken from the interview text of the

¹⁹ See Appendix C (p310) for list of conference presentations.

²⁰ A constitutive pattern is one that exists in all the data and explains the link or relationship between the themes (Diekelmann, Allen & Tanner, 1989).

participants. Responses and suggestions from my PhD supervisory team were incorporated into the final draft.

On two occasions, I attended the Institute for Interpretive Phenomenology in the USA. This institute was facilitated by Professor Diekelmann and colleagues and provided advanced training on the hermeneutical approach to data analysis used in this study.

3.6 RIGOUR OF THE STUDY

The hermeneutical phenomenological methodology employed in this study implied that the background context and perspective of the researcher informed the interpretation of the data. Interpretation was based on the fusion of the participants' perspective with the researcher's perspective, to achieve a more in-depth understanding of the phenomena under study (Koch, 1996; Draucker, 1999). However, the challenge of using this hermeneutical approach was the control of bias, to ensure that my interpretations were an accurate portrayal of the participants' experience of ESRD and haemodialysis therapy. According to Wolcott (1995), bias will only influence a study if the researcher does not acknowledge it. If bias is acknowledged, it can lend focus to the study.

The approach to data analysis by Diekelmann, Allen & Tanner (1989) served to control bias and enhance rigour in the study. As mentioned previously, this approach to data analysis involved incorporating other researchers in the interpretation of the data. Multiple interpretations of the data at every stage of the analysis served to challenge, question, and confirm my interpretations of the data.

By reading both the narratives of the participants, and my interpretations, the other researchers involved in the interpretive process served to enhance the interpretations. This process of strengthening the interpretations ensured that interpretations were substantiated and accurate, and subsequently enhanced the rigour of the study.

A continual process of reading, writing, thinking, and dialogue occurred throughout this hermeneutical study. The prolific handwritten accounts generated repeated cycles of critical reflection, which facilitated the progression of the study. Furthermore, these cycles of critical reflection enhanced the rigour of the study. As I had previously

worked as a nurse on haemodialysis units, I realised that this background context and perspective would influence the interpretations and decisions I made throughout the study. Therefore, there was a need to identify the perspectives, preconceptions, and assumptions I had about the topic, which might overly influence or bias my interpretation of the participants' accounts.

By critically thinking, reflecting, and writing throughout the study, I was able to heighten my awareness of the preconceptions and assumptions I had about the study topic. Indeed, this is why Kahn (2000b) recommended a process of critical reflection within hermeneutical phenomenological studies. The author stated that this process helped to identify preconceptions, assumptions, and prejudices about the research topic, which could lead to bias.

It is important to point out that the aim of reflection was not to suspend or “bracket” my assumptions or presuppositions, as the Husserlian/psychological approaches to phenomenology have contended. Unlike a Husserlian or psychological approach to phenomenology, the suspension or “bracketing” of presuppositions is not deemed appropriate within a Heideggerian phenomenological study. The aim of these written reflective accounts was merely to heighten my awareness of these presuppositions, so they would not overly influence my interpretation of the data.

The written accounts maintained during this study also provided a record of the thoughts, interpretations, and decisions I made throughout the various stages of the research process. Molzahn & Shields (1997) described the ability to maintain comprehensive notes relating to the progression of the study as an element of rigour. The database created in *Microsoft Access* also provided a record of the categories and themes developed during data analysis.

Some authors suggested that the credibility of qualitative studies was enhanced through prolonged engagement with the participants (Leininger, 1994; Streubert & Carpenter, 1995; Molzahn & Shields, 1997). I spent a substantial amount of time with each participant, before, during, and after each interview. In addition, by conducting two interviews with the participants, I ensured that prolonged engagement and rapport was attained. The follow-up interview with the participants allowed gaps in the data from

the first interviews to be addressed. It also enabled further information and clarification about their experiences to be documented. This process facilitated a more in-depth description of the richness and complexity of the participants' experience to be generated, which enhanced the credibility of the findings.

3.7 ETHICAL ISSUES

Lo Biondo-Wood & Haber (1998) identified three basic ethical principles to guide all research investigations, which included respect for persons, beneficence, and justice. The principle of respect for persons signified that persons had the right to self-determination and the freedom to participate, or not to participate in research (Lo Biondo-Wood & Haber, 1998; Burns & Grove, 2001). Beneficence was described as an obligation to do no harm and maximise the possible benefits for individuals who participated in research (Lo Biondo-Wood & Haber, 1998). The principle of justice implied that human beings should be treated fairly during research studies (Lo Biondo-Wood & Haber, 1998).

These principles were upheld throughout all stages of this hermeneutical study on the person's experience of ESRD and haemodialysis therapy. Formal written ethics approval to conduct the study was given by the Research Ethics Committee at the study hospital. Permission to carry out the study in their clinical area was granted by the consultant nephrologists and the nurse managers of the renal unit at the study hospital.

The participants were informed of the nature and purpose of the study, the main features of the design, as well as the possible outcomes of the study. Participants were allowed time to ask any questions regarding the study and were then requested to sign a consent form.²¹ A copy of the signed informed consent form was given to the participants, which included a brief background to the research, contact information, and details about the purpose of the study.

²¹ See Appendix D (p311) for a copy of the informed consent form.

The participants were informed that they had the right to participate or refuse to participate in the research and that they could withdraw from the study at any time. The privacy and confidentiality of participants was assured throughout the study by assigning a pseudonym to each participant and ensuring that their names never came in contact with the data. All data from the interviews were locked in a cabinet and stored at a separate location from the study hospital.

The qualitative interview format used in the study required the participants to discuss the effects of ESRD and haemodialysis on their lives. Cohen (2000) suggests that patients find qualitative interviewing helpful, as it allows them to talk about experiences that they have never had the opportunity to discuss before. However, it was also recognised that describing the experience of illness could potentially generate feelings of sadness and distress amongst some participants. Therefore, I ensured that the risk of distress was minimised during the interviews with the participants.

For instance, the conversational style of the interview allowed the participants to control many of the topics raised and discussed during the interviews. In addition, the participants were not pressurised in any way to talk about experiences, which appeared to upset them. Prior to conducting the interviews, I had a specific plan of action that would be used in the event that a participant became upset during the interviews.

Firstly, the research interview and tape recorder would be stopped, and I would spend time with the participant responding to his/her distress. Secondly, I would inform the nurses on the haemodialysis unit that the participant had become upset during the interview, and would require some follow-up support. Finally, the participant(s) would also be referred for follow-up support from the Renal Nurse Specialist on the haemodialysis unit. This nurse held a recognised qualification in counselling and was available to provide support and counselling both during and after the study. Fortunately, this action plan was not initiated, as none of the participants became distressed during or after the interviews.

3.8 CONCLUDING COMMENTS

This chapter discussed the methodological features of the study. A hermeneutical phenomenological approach was employed, based on the philosophical perspective of Martin Heidegger. In particular, Heidegger's (1962) notion of time or temporality was central to his phenomenological analysis of existence or being. This philosophy guided all stages of the research process.

To summarise, a purposive sampling strategy was used to select participants who would provide an in-depth description of their experience of ESRD and haemodialysis therapy. Data were collected using in-depth qualitative interviews, which resembled a conversation. A hermeneutical approach to data analysis by Diekelmann, Allen & Tanner (1989) was used to analyse the interview data. The findings gleaned from this hermeneutical analysis of the data will be discussed in detail in the upcoming chapter.

CHAPTER 4 : FINDINGS

This chapter presents the interpretive findings of the study. The experience of waiting was identified as a constitutive pattern in this study.²² As mentioned earlier in the research methodology chapter, a constitutive pattern was an overarching pattern that existed within the data from all participants. It explained the link or relationship between the themes created from the data (Diekelmann, Allen & Tanner, 1989). The experience of waiting consisted of three themes:

1. *Lost Time*
2. *Waiting for a Kidney Transplant*
3. *Communicating with Nurses: Myth versus Reality.*

The participants' accounts illustrated that they spent a lot of time waiting when they attended haemodialysis therapy. The time spent waiting was unrelated to their everyday lives, and held them back from their everyday activities. Therefore, the participants interpreted the time spent waiting, as time lost out of their everyday lives.

The theme *Lost Time* was constituted by two sub themes:

1. *Killing Time*
2. *Wasting Time*

The participants described their efforts to kill time, while they waited for haemodialysis therapy to end. They also described their experience of wasting time, as a result of waiting unnecessarily before and after haemodialysis therapy. The continuous nature of haemodialysis therapy meant the participants had to repeatedly endure the experience of waiting each week. Therefore, they described the distress, which accompanied this experience.

A successful kidney transplant offered the participants freedom from the confines of long-term haemodialysis therapy, and the possibility of returning to an almost normal lifestyle. However, a suitable donor match had to be established to ensure the success of transplantation. Therefore, the participants were placed on a transplant waiting list until a suitable donor match was located and transplantation could proceed. Since there are a

²² For a visual display of the themes and sub themes, which constituted the participants' experience of waiting, see Figure 1 (p129).

limited number of donor kidneys available, the waiting process took a substantial amount of time for some participants.

The experience of waiting for a kidney transplant was significant for the participants in the study. The theme *Waiting for a Kidney Transplant* consisted of three sub themes:

1. *Living in Hope.*
2. *Uncertainty.*
3. *Being on Hold.*

The participants' accounts highlighted their experience of living in hope, while they waited for a kidney transplant. The information they received from the healthcare team in relation to the "average" waiting time for a kidney transplant, contributed to their experience of hope. Because of this information, several participants expected to receive a kidney transplant within a relatively short duration of time. However, when they exceeded the average waiting time for a kidney transplant, they became uncertain.

When confronted with uncertainty, some participants were unable to contemplate possibilities for the future. Furthermore, the restrictions of haemodialysis therapy prevented them from participating fully in their everyday activities. Consequently, they described their experience of being on hold, while they waited for a kidney transplant.

It is proposed that Heidegger's phenomenological notion of time was embedded within the participants' experience of waiting, described in the themes *Lost Time* and *Waiting for a Kidney Transplant*. It seemed that that the experience of waiting described in these themes highlighted the threefold structure of originary temporality to the participants.²³ This temporal feature of the participants' experience of waiting characterised Heidegger's (1962, 1995) account of anxiety and boredom. According to Heidegger (1962, 1995), anxiety and boredom were existential moods. It is necessary to provide an account of Heidegger's perspective of mood before moving onto the description of the participants' description of waiting, portrayed in the study.

²³ See page 93 for the previous discussion on originary temporality.

Heidegger's (1962) description of anxiety as an existential mood was strikingly different to the psychological perspective of this concept, portrayed in the existing literature related to the person with ESRD. Within this literature, anxiety and uncertainty were discussed interchangeably and were deemed psychological responses to the losses and lifestyle disruptions created by ESRD and dialysis therapy.²⁴

The experience of boredom was not specifically addressed in the literature related to the person's experience of ESRD. Indeed, Barbalet (1999) claimed that while boredom was a common experience, it was usually more taken for granted than explored. Correspondingly, Svendsen (2005, p8) declared that "very few people have any well-thought-out concept of boredom. It is usually a blank label applied to everything that fails to get our attention". However, based on a review of the existing literature on boredom, it seemed that the concept was largely deemed a subjective or cognitive response that occurred within the individual (Hill & Perkins, 1985; Perkins & Hill, 1985; Farmer & Sundberg, 1986; Vodanovich & Kass, 1990; Seib & Vodanovich, 1998; Vodanovich, 2003; Lee & Mittelstaedt, 2004).

If we recall, this predominantly psychological perspective of moods emanated from the Cartesian tradition. This tradition led to thinking in terms of two worlds: one inner, subjective world, which consisted of conscious processes, and one outer, objective world, which was outside or independent of the person (Hollis, 1994). This belief encouraged us to assume that our moods were either a subjective state, which came from inside the person, or an objective state, which came from outside the person. However, Heidegger's (1962) notion of mood rejected this assumption and claimed that moods were neither purely subjective nor objective. He conveyed that mood "comes neither from 'outside' nor from 'inside', but arises out of Being-in-the-world, as a way of such Being..." (p176-7).

Although Heidegger (1962) sometimes used the term *state-of-mind* to describe mood, his notion of mood did not refer to a subjective, private mental state. Indeed, he emphasised that the fact that moods were public, and could be shared with other people, confirmed that moods were not merely subjective (Dreyfus, 1991; Wrathall, 2006).

²⁴ See page 49 for the discussion on uncertainty and anxiety in the literature review.

Heidegger (1962) claimed that moods were not merely private feelings derived from consciousness and projected over a situation. Consequently, he rejected the idea that moods should be understood from a psychological perspective as feelings, experiences, or consciousness.

It is important to note that when Heidegger (1962, 1995) made this point, he was not setting out to dispute the psychological characterisation of feelings and experiences. Rather, by linking mood to existence, Heidegger offered us an alternative way of understanding these everyday feelings and experiences, which came before all theoretical categorisation. Therefore, Heidegger deliberately used the term mood, to show us that moods were not to be confused with the psychological understanding of feelings and emotions, which currently existed.

If mood was not a subjective state, then based on the Cartesian tradition, we were led to assume that it was an objective state, something that came from outside of the person. In contrast, Heidegger's account suggested that moods did not purely exist outside the person either. Instead, his analysis of mood signified that moods were a product of our existence, and subsequently arose from our "being-in-the-world". In order to explicate more clearly, what Heidegger meant when he spoke about moods, anxiety and boredom will now be discussed.

Heidegger (1962) described boredom and anxiety as fundamental existential moods. He signified that moods stemmed from our "thrownness" into the world. If we recall from the previous discussion on the originary past, Heidegger (1962) used the term thrownness to express the way we were thrown into the world.²⁵ Because we were thrown into the world, we had to submit to things that we had little or no choice about. For instance, the place we were born, our physical features, the resources in our environment (Wrathall, 2006). More importantly, we had to succumb to our *thrownness into death* i.e. our finite existence.

²⁵ See page 93 for the previous discussion on originary temporality.

According to Heidegger (1962, 1995), anxiety (*Angst*) and boredom (*Langeweile*), as two fundamental existential moods, disclosed the finitude of Dasein's existence i.e. its thrownness into death. These moods achieved this by illuminating the threefold structure of originary temporality, which formed the basis of the care-structure of Dasein's being (Heidegger, 1962).

If we recall, Heidegger (1962) described originary temporality as a basic structure of Dasein's being. He said that originary temporality was an ecstatic unity consisting of the past, present, and future. The three ecstases of originary temporality formed a unified whole, with a projective character based on the originary future. As a result of originary temporality, Dasein was always projecting into possibilities in the future. It was this projection, which made death a possibility that lay before Dasein throughout its existence (Mulhall, 2005).

Thus, from Heidegger's perspective, death was not seen as biological death (Mulhall, 2005). It was not merely an event, which occurred at the end of one's life. Instead, death was a feature of Dasein's thrownness. By being thrown into the world, we were also thrown into death. Therefore, death was viewed as one possibility of our existence (Mulhall, 2005). Heidegger (1962) illustrated this point when he said "Let the term "*dying*" stand for that *way of Being* in which Dasein *is towards* its death" (p291).

By illuminating the ecstatic structure of originary temporality, anxiety and boredom highlighted that death was one possibility of Dasein (Hoffman, 2005). According to Heidegger (1962, 1995), the moment when the finitude of existence was disclosed to Dasein was the *moment of vision*. It was the decisive moment where Dasein was prompted to live in either the authentic or inauthentic mode of existence. By highlighting the finitude of existence, anxiety and boredom prompted Dasein to live in either an authentic or inauthentic mode of existence.

Heidegger (1962) described the inauthentic mode of existence as our absorption in everydayness. He signified that Dasein tended to flee when confronted with the possibility of death (Mulhall, 2005). Therefore, to avoid reflecting on its death and finitude, Dasein absorbed itself in everydayness (Mulhall, 2005). As previously

mentioned, Heidegger (1962) used the term “falling” to describe the everydayness of Dasein.²⁶

In falling, we were so caught up in our tasks and activities that we did not reflect on our existence. Instead, we merely engaged in everyday idle talk and gossip. We were in the state of “*Das Man*”, which meant we were the same as everyone else and experienced things collectively as they did (Heidegger, 1962). Therefore, to avoid facing the finitude of existence, Dasein absorbed itself in the everyday tasks and activities it performed in world-time. Heidegger (1962) referred to this absorption in everydayness, as the inauthentic mode of existence. It was the mode of existence we were familiar with in our everyday involvements in the world.

On the contrary, to live in the authentic mode of existence, Dasein had to reflect on the finitude of its existence, and take responsibility for this existence. Heidegger’s concept of authenticity consisted of *forerunning resoluteness*. According to Gelven (1989), resoluteness was closely linked to freedom and choice. To be resolute meant to be free to choose our possibilities in life. It implied that Dasein was solely responsible for the way it existed and took ownership of this existence (Gelven, 1989; Mulhall, 2005). Forerunning meant grasping the possibility of death and finitude, while simultaneously being able to project into possibilities in life (Blattner, 1999; Carman, 2005).

When anxiety and boredom disclosed the finitude of existence, the person was prompted to live in either the authentic or inauthentic mode of existence. As Mulhall (2005) pointed out, most people tended to flee and live in the inauthentic mode of existence when confronted with death. According to Heidegger, the everyday moods experienced by the person depicted his/her evasion from the finitude of existence (Hoffman, 2005). When the person was absorbed in the everydayness of the inauthentic mode of existence, s/he was able to conceal or cover over the finitude of existence. Thus, the person experienced pleasant everyday moods, such as satisfaction, contentment, enjoyment, happiness, hope etc.

²⁶ See page 97 for the previous discussion on falling.

However, if for some reason the person was unable to live in the authentic or inauthentic mode of existence, s/he was subsequently unable to entirely conceal the finitude of existence. The inability to live in either mode of existence culminated in the unpleasant and distressing moods experienced by the person on an everyday basis, such as sadness, depression, despair, irritation, frustration, anger, and so forth.

Therefore, anxiety and boredom, as two fundamental existential moods, disclosed the person's thrownness into death (Hoffman, 2005). By doing this, they provided the basis for the moods experienced by the person in everyday life (Dreyfus, 1991; Hoffman, 2005). Consequently, from Heidegger's perspective, all our everyday moods were essentially inauthentic moods (Hoffman, 2005). They characterised our inability to live in an authentic mode of existence. In other words, they were evasions from our thrownness into death, or as Heidegger (1962) puts it "they disclose Dasein in its thrownness, and-proximally and for the most part-in the manner of an evasive turning-away"(p175).

It is important to point out, that the authentic and inauthentic modes of existence were two modes of originary temporality (Blattner, 1999). Heidegger (1962) stated that "Temporality temporalizes, and indeed it temporalizes possible ways of itself. These make possible the multiplicity of Dasein's modes of Being, and especially the basic possibility of authentic or inauthentic existence" (p377). Consequently, this implied that the threefold structure of originary temporality remained unified in both modes of existence.²⁷ By choosing to live in the authentic mode of existence, Dasein was aware of the finitude of its existence, but still projected forward into possibilities in the originary future. Hence, it acted in the present, based on its affectedness from the past, to project forward into some possibility in the future.

By choosing to live in the inauthentic mode of existence, essentially the same thing occurred. Except in the inauthentic mode of existence, Dasein did not acknowledge its finite nature. Instead, it allowed itself to be absorbed in the everyday tasks and activities, which occurred in world-time to avoid this realisation. Nonetheless, in both modes of existence, the threefold structure of originary temporality remained unified.

²⁷ See page 93 for the previous discussion on the threefold structure of originary temporality.

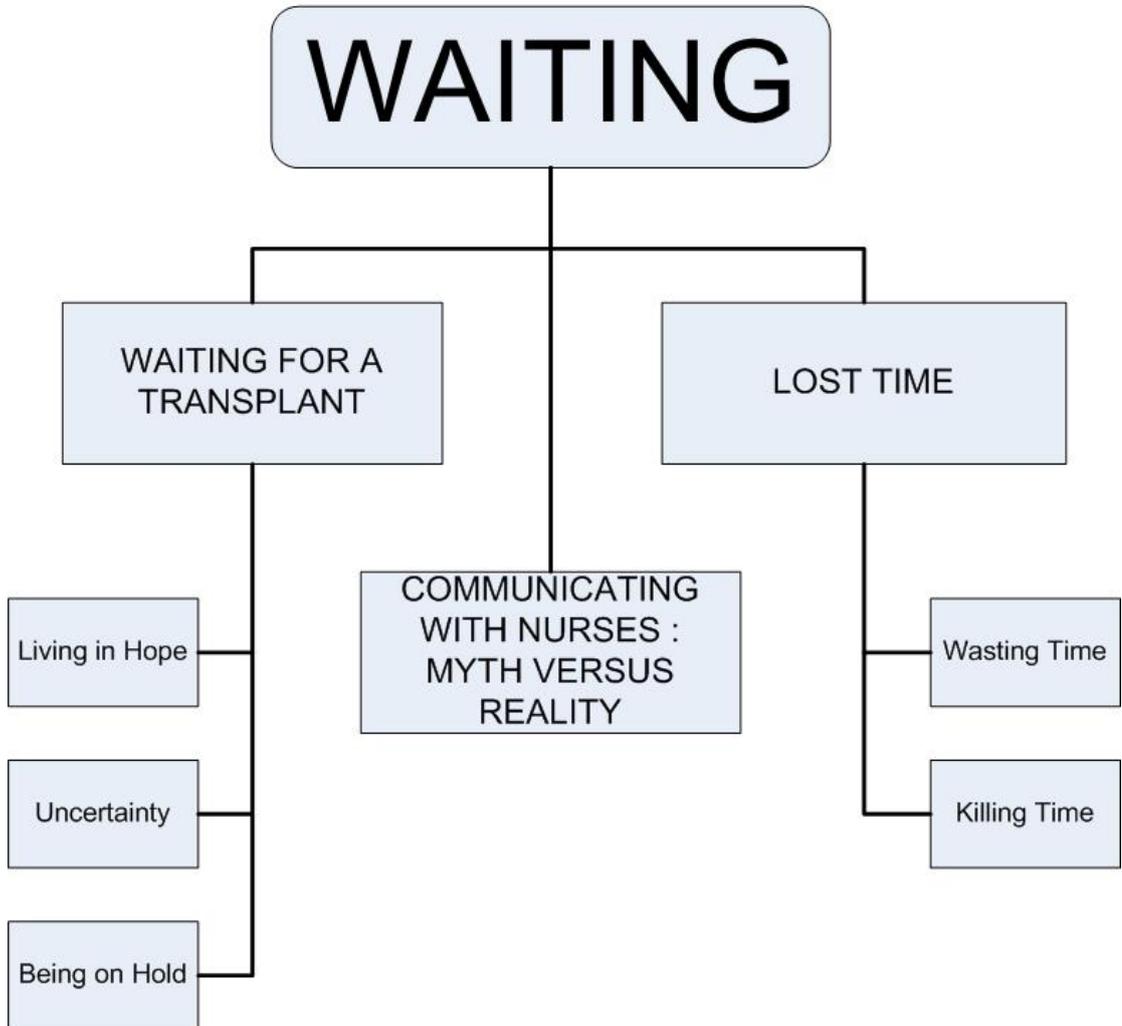
It is proposed, that the experience of waiting, described in the themes *Lost Time* and *Waiting for a Kidney Transplant* highlighted the unified structure of ordinary temporality to the participants. This subsequently culminated in the fundamental existential moods of anxiety and boredom, described by Heidegger (1995). The experience of anxiety and boredom prompted the participants to live in either an authentic or inauthentic mode of existence. However, because of the persistent nature of their experience of waiting, the participants were unable to live in either mode of existence.

It is suggested that the participants' inability to live in either mode of existence because of the experience of waiting, created a disruption in the threefold structure of ordinary temporality. Moreover, it culminated in a range of distressing moods, which intensified as the waiting continued indefinitely. These characteristic features were contained within the narrative accounts of the participants' experience of waiting.

Although the participants repeatedly attended the haemodialysis unit, their distressing experience of waiting did not appear to be recognised by the healthcare professionals responsible for their care. In particular, the nurses on the haemodialysis unit were the primary caregivers for these participants. Despite regular nurse-patient interaction, the narratives of the participants exemplified that the nurses rarely communicated with them during their treatment. Hence, the nurses did not address or attend to the participants' distressing experience of waiting.

The participants' perspective of communicating with nurses during haemodialysis therapy is discussed in the third and final theme in the study. The theme is labelled *Communicating with Nurses: Myth versus Reality*. A visual display of the themes and sub themes, which constituted the participants' experience of waiting, is provided in Figure 1 (p129).

FIGURE 1. EXPERIENCE OF WAITING



The findings of the study will now be presented, beginning with the theme *Lost Time*. Where possible, two interviews were conducted with each participant. Therefore, a participant identification number (ID number) and interview number are attached at the end of each narrative that is discussed in the findings. The participants' ID numbers are contained in Table 1 (p131). Hence, 1/1 refers to the first interview with Amy, while 1/2 refers to the second interview with Amy; 4/1 refers to the first interview with Connie, while 4/2 refers to the second interview with Connie, and so forth. To ensure confidentiality was maintained, the names assigned to the participants are pseudonyms. The participants' age, and length of time on haemodialysis therapy are also contained in Table 1 (p131). As the table illustrates, some participants' circumstances had changed by the time of the follow-up interview. Also, three participants i.e. Amy, Elena, and Harrison, were deemed physically unfit for transplantation, so they were not on the transplant waiting list and knew they would remain on dialysis for the rest of their lives.

Table 1: Participant Information

ID Number	Pseudonym	Age	Number of Years on Haemodialysis Therapy	
			1 st Interview	2 nd Interview
1	Amy	54	1 year <i>(Not suitable for transplantation)</i>	2 years <i>(Not suitable for transplantation)</i>
2	Ali	55	2 years	3 years
3	Alex	31	1 year	Transplanted three months earlier.
4	Connie	63	10 months	1 year 10 months
5	Carl	30	1 month	1 year 1 month
6	Chris	40	1 year 6 months	2 years 6 months
7	Danny	49	1 year 7 months	2 years 7 months
8	Donna	34	2 years	3 years
9	David	59	1 year	2 years
10	Elena	57	1 year 6 months <i>(Not suitable for transplantation)</i>	2 years 6 months <i>(Not suitable for transplantation)</i>
11	Gloria	57	4 years 5 months	Deceased
12	Harrison	66	4 months <i>(Not suitable for transplantation)</i>	1 year 4 months <i>(Not suitable for transplantation)</i>
13	Jeff	32	1 year	2 years
14	John	51	5 years	Re-located to another country.
15	Liz	44	2 years 9 months	Transplanted one month earlier.
16	Nancy	43	4 years	Transplanted eleven months earlier.

4.1 THEME 1 - LOST TIME

The findings suggested that the participants spent a lot of time waiting when they attended haemodialysis therapy. The time spent waiting was deemed empty and unproductive. It was unrelated to the participants' everyday lives, and held them back from performing everyday activities. Therefore, they interpreted the time spent waiting, as time lost out of their everyday lives. The experience of waiting was distressing for the participants and was associated with uneasiness, irritation, frustration, anger, boredom, and despair. The continuous nature of haemodialysis therapy meant the participants had to repeatedly endure the experience of waiting each time they attended the treatment.

The theme *Lost Time* was constituted by two sub themes:

1. *Killing Time*
2. *Wasting Time.*

The participants' accounts signified that they spent a lot of time during haemodialysis therapy merely waiting for the treatment to end. Therefore, they described their attempts to kill time, in an effort to overcome the unpleasant experience of waiting during haemodialysis therapy. The participants also reported that they spent a substantial amount of time waiting unnecessarily before and after the treatment. They described the time spent waiting needlessly as wasting time.

The follow-up interview illustrated that a small number of participants were able to overcome the experience of waiting when they attended haemodialysis therapy. A detailed discussion of each of the sub themes will now be provided with the accompanying narratives of the participants.

4.1.1 SUB THEME - KILLING TIME

The participants described their experience of waiting impatiently for haemodialysis therapy to end. While waiting, the time seemed to pass very slowly. Therefore, they tried to kill time in an effort to overcome the unpleasant experience of waiting during haemodialysis therapy.

The participants used various strategies to kill time during the treatment, such as sleeping, reading, doing puzzles, watching television/DVDs, and having a cup of tea. However, they were physically attached to the haemodialysis machine, which restrained the variety of activities they could perform during the treatment. This meant they had to repeatedly rely on the same strategies to kill time during haemodialysis therapy.

With the exception of sleeping, there seemed to be no pastime, which could sufficiently kill time for the duration of haemodialysis therapy. Therefore, the participants spent a lot of time merely watching the clock, while they waited for the treatment to end.

It seemed reasonable to suggest that communicating with nurses was an appropriate way for the participants to kill time during haemodialysis therapy. However, the participants' accounts indicated that the nurses rarely spent time communicating with them during their treatment.²⁸ Hence, these nurses did not attend to the participants' distressing experience of killing time, while they waited impatiently for haemodialysis therapy to end. This was reflected in the environment of the haemodialysis unit, which offered little to enable the participants to kill time during the treatment.

For instance, there were a small number of televisions provided on the unit, which had to be shared by a number of patients. Consequently, the participants were unable to freely choose the programmes they wanted to watch during haemodialysis therapy. Some participants highlighted their desire to talk to other patients as a way of killing time during their treatment. However, the layout and organisation of the haemodialysis unit did not facilitate communication between patients.

²⁸ The lack of nurse-patient communication will be discussed in the upcoming theme titled *Communicating with Nurses: Myth versus Reality*.

The participants' accounts signified that the strategies they employed to kill time during haemodialysis therapy did not have a specific purpose or outcome. They did not represent the experience of leisurely passing time, which was normally associated with everyday pastimes. Instead, these strategies were merely a way of killing time, so that the wait for haemodialysis therapy to end would be over as quickly as possible.

The participants signified that their efforts to kill time did not occupy or fill the entire duration of haemodialysis therapy. Therefore, they had nothing to do for a substantial amount of their treatment time, which culminated in uneasiness, irritation, frustration, and boredom. The repetitive nature of haemodialysis therapy meant the participants had to persistently endure the experience of waiting each week. The follow-up interview with the participants allowed their experience of killing time to be documented overtime. However, in many instances, the participants were unable to overcome the experience of waiting during haemodialysis therapy.

For instance, in both interviews with Ali, a 55-year-old male, he described his experience of killing time, while he waited for haemodialysis therapy to end. The following account was taken from the first interview with Ali.

He said:

The first two hours are not too bad...the last two because you're looking forward to coming off, you're getting tired and you're getting restless, so the time does drag, it would be like the four hours put together...you can watch television, and you can read but I find it hard to concentrate here to read, I find it hard even to watch television...with the noise of the television and with the noise of the machines...and sometimes the earphones would not work...I find there's so much going on in the unit that it's not easy to concentrate on reading...some people can go to sleep on the machine, I can't, I couldn't do that. (2/1)²⁹

Ali's account indicated that the time dragged during the last two hours of haemodialysis therapy. While he tried to kill time by reading and watching television, these strategies did not kill time for the entire duration of the treatment. Occasionally the individual headphones did not work, which made it impossible for Ali to hear the television. In

²⁹ Within the findings section, the use of (...) within the narratives signifies the natural pauses contained within the participants' speech during the conversation.

addition, there were times when the excessive noise on the haemodialysis unit hindered his ability to read or sleep.

Ali's account emphasised that the strategies he used to kill time did not fill the entire duration of haemodialysis therapy. Hence, he spent the last two hours with essentially nothing to do, except wait impatiently for the treatment to end. Embedded within Ali's description of waiting was his predominant focus on clock time.

As his narrative continued, Ali expressed his desire to talk to other patients, in an effort to kill time during haemodialysis therapy. However, he claimed that he was frequently rotated to different dialysis stations, which prohibited him from getting to know other patients. Furthermore, the placement of the haemodialysis machine effectively blocked him from communicating with other patients during treatment.

The unit is so big that you can end up beside anybody that you don't know...and the machine kind of blocks you from talking anyway...If you had somebody beside you and were talking to somebody, it [time on dialysis] would go faster...whether it was about the machine or about how they were feeling, it [time] certainly would [go faster], there is no doubt about that. (2/1)

Similarly, Nancy, a 43-year-old female also highlighted her experience of killing time, while she waited for haemodialysis therapy to end. Nancy signified that the time spent during haemodialysis therapy was long and drawn out. It held her back from engaging in everyday activities and culminated in the irritating feeling of wasting time.

According to Nancy, sleeping was the most effective way to make the time disappear during haemodialysis therapy. Therefore, she tried to tire herself out during the day, so she would be able to sleep throughout the treatment. However, there were occasions when Nancy was unable to sleep. On these occasions, she used to perform various activities in an effort to kill time, such as reading, listening to music, and watching movies on her portable DVD player. Since Nancy was physically attached to the haemodialysis machine via her arteriovenous fistula (AVF), her activities were

particularly confined during treatment.³⁰ Therefore, she repeatedly rotated the same activities in an effort to kill time.

Nancy's account verified that her efforts to kill time did not sufficiently occupy the entire treatment time of haemodialysis therapy. Therefore, she was unable to overcome the empty and unproductive time spent waiting for the treatment to end. Like Ali, Nancy's account confirmed that the environment of the haemodialysis unit did not facilitate her ability to kill time during treatment. She had to share a television with other patients, which meant she was unable to choose the programmes she wanted to watch.

Here is Nancy's account:

Some nights it's very long [especially] when you want to get home and get things done...you're just thinking to yourself...please get me off [the machine]...I do things during the day to tire myself out so I know when I get here [to the dialysis unit] I will sleep...the night I can't sleep is very long...I came here one night without my book and my music, and the night was really long, so now I bring in a DVD player on the odd night so I can watch a film...every so often I get a very long night when I get irritated and I want to go home ...I mean they brainwash you in here with Coronation Street [laughs] and I hate it ...so if you want to watch TV, you have to watch that or whatever is already on...that's why I bring in my own music and books...just to keep changing the night, otherwise it's just the same old routine ...an odd night you might get caught up in a film...Your tied ! The machine is so big...I look at it as if I'm stuck to that bloody machine. (16/1)

Gloria also conveyed her experience of killing time, while she waited to finish haemodialysis therapy. She signified that the time dragged, so she employed various strategies to kill time during the treatment.

Like Nancy, being physically attached to the haemodialysis machine via her AVF meant Gloria had to repeatedly rely on the same activities to kill time. However, her account implied that these activities did not keep her occupied for the entire duration of haemodialysis therapy. Consequently, she spent a lot of time watching the clock, while

³⁰ Patients with an arteriovenous fistula or graft have two large bore needles inserted in one of their arms during haemodialysis therapy, to allow access to the circulation. Consequently, these patients are required to keep their arm still throughout the treatment. This severely restricts their movement and ability to perform pastimes.

she waited impatiently for the treatment to end. The following account was taken from my first interview with Gloria. Sadly, she died within the following year.

It [time on dialysis] drags, but I could be lying here for an hour after dialysis and it wouldn't bother me, but when you're attached to that [dialysis machine] you're just watching the clock the whole time...nearly the whole time, unless I get engrossed in my book, and I have my radio and my bridge game as well, so I kind of rotate them all around ...I don't know how to describe it really, it's just that when you go on that [machine], you look at the clock and you say two hours to go, an hour and a half, only a half an hour left...once you're hooked up to there [dialysis machine] you're watching the clock, it's amazing really. (11/1)

Gloria's narrative gave the impression that the strategies she used to kill time did not have a specific purpose or outcome. Instead, they were merely used for the sole purpose of getting through the empty time during haemodialysis therapy. Embedded in her account was the excruciating experience of waiting impatiently for dialysis to end. Indeed, as Gloria's narrative progressed, she emphasised the need for activities to be available on the unit, which would make the time spent waiting more productive.

I often think [laughs] wouldn't it be lovely if you could have a massage on your feet...or maybe some kind of bicycle that you get a bit of exercise while you're here, that would be nice. (11/1)

In both interviews with Connie, she also described her experience of killing time, while she waited for haemodialysis to end. She declared that the time passed slowly during haemodialysis therapy. Therefore, it was essential to be able to perform activities to kill time for the duration of the treatment.

Connie said she enjoyed watching television as a way of killing time. In particular, she expressed her desire to watch a popular Friday night talk show. However, the television had been removed from the dialysis station that Connie was regularly assigned to on a Friday night. This meant she was currently unable to watch her favourite programme.

There are some nights and you'd say it [time] is slow...but you see I do a crossword and I read, but for the people that don't do that, it must be an eternity for them...but having said that, there's always somebody going up and down and time passes that way...it doesn't go that fast now either, but when you do have something to occupy your mind it's better...now I must say I like to watch television...On Friday night the group of us [patients] would be here and we might like to watch the Late Late Show, but I can't because there's no telly over there [points to other side of dialysis unit]...I don't know whether they'll [TVs] ever

come back again, but they used to have them and they're not there now, well that one isn't. (4/2)

Correspondingly, the experience of killing time was also characterised in the narratives from both interviews with Alex. Alex indicated that the time passed slowly during haemodialysis therapy. Therefore, he read the paper, and watched television in order to kill time. However, like the other participants, Alex had an AVF, which significantly restricted his movement. Therefore, the strategies he employed did not sufficiently kill time for the entire duration of his treatment.

Since Alex was unable to kill time during haemodialysis, he had nothing to do except wait for the treatment to end. The predominant focus on clock time was entrenched within his account.

It [time] can be slow enough yea...four hours is long enough now, and not a whole lot to do...I read the paper for the first hour, that passes about an hour, and after that, it's just look around you, then I look at the telly or just rest for the other three hours...It can be hard enough, just knowing you can't get out [of bed], you mightn't have to get out but just the fact that you're tied to the bed is probably the biggest thing...yea it's boring enough now...the first hour doesn't go too bad but the second, third, and fourth, there isn't a lot to do, I'm kind of looking forward to the cup of tea...usually you have probably around an hour left after you get the tea. (3/1)

Beneath Alex's account was the boredom he experienced, while he waited for haemodialysis therapy to end. Indeed, the highlight of the treatment for Alex occurred when he received a cup of tea toward the end of the treatment. It seemed the timing of the cup of tea served as a reminder to Alex that his waiting would soon be over.

Other participants also described their experience of killing time, while they waited for haemodialysis to end. For example, Donna was an insulin dependent diabetic, and as a result was partially blind. She indicated that the time was "very long" during haemodialysis therapy. In particular, the environment of the unit offered little to enable her to kill time during treatment. Donna stated that the televisions on the unit were mounted from the ceiling, which meant they were too far away for her to see. Furthermore, the deterioration in her sight limited her ability to read during the treatment.

Donna's account signified that she had nothing to do during haemodialysis therapy except wait for the treatment to end. Therefore, she emphasised the need for activities to be provided, which would make the time during haemodialysis more interesting and productive.

It [time on dialysis] is very long and the televisions are up too high...I bring in my CD Walkman so I can listen to music. I used to be an excellent reader but I got diabetes and now I'm left without my eyesight...I mean if you had computers to come in and work on, it would be great, it would create something to do, it would be something to pass the time away. (8/1)

In the follow-up interview with Donna, she had managed to develop new ways of killing time during haemodialysis therapy. She had recently received the gift of a portable DVD player and used this to pass the time on dialysis. In addition, Donna had changed her dialysis time to the evening. This meant that she was on haemodialysis therapy with a different group of patients who engaged in conversation with her during treatment.

My birthday was about two weeks ago and I got a portable DVD player...Because I'm going blind, I can't see the televisions up there...and you can't hear them, so I've got the little DVD player that I can have beside me...it's going well...I can watch the DVD and play CDs on it as well, you can listen to music on it as well if you wanted to...and another thing that is good is that I'm [on dialysis] later now...I used to be on in the morning but I'm in the evenings now and a group of the patients [on dialysis], they'd all have good fun and tell you a story or two. (8/2)

Despite these new pastimes, Donna insisted that she was still unable to kill time for the entire duration of the treatment. Therefore, she spent the last hour of dialysis just "counting the minutes", while she waited impatiently for the treatment to end.

It's like watching paint dry...Molly [Donna's carer] sits at the end of the bed and we'd be talking and I'd say to her "how long have I left now", and she'd say "fifty five minutes"...and then I'd say "Is that clock going" and she'd say "yes", and that's the way I am for the last hour, it drives me nuts, it [time] is so long, why, I don't know, because it is only an hour...you're counting the minutes all day while you're in here. (8/2)

The uneasiness, irritation, and frustration caused by Donna's experience of waiting during haemodialysis therapy were palpable within her account.

Likewise, in both interviews with Elena, she portrayed the distressing experience of killing time, while she waited for dialysis therapy to end. Elena specified that the last hour was the most distressing, because she had nothing to do. Implicitly contained in her account was the irritating feeling of wasting valuable time, while she waited for the treatment to end. Therefore, she emphasised the need for activities on the unit, which would enable patients to kill time and overcome the unpleasant experience of waiting.

I think it would help people who are on dialysis to stimulate them, rather than just lying there...to have some form of activity that you can do while you're just lying there...the last hour is the worst for me, it just seems to drag...you're watching the clock all the time, you can't see the one on the machine but you can see the ones on the wall, and you're constantly thinking "oh is it only ten minutes since the last time I looked"...It's just waiting really I suppose...just waiting to come off [dialysis]. (10/2)

In contrast to the other participants, the first interview with David demonstrated that he had no problems killing time during haemodialysis therapy. Instead, he expressed the pleasant experience of leisurely passing the time during his treatment.

I don't mind my time on the machine, I'm usually in good form...it doesn't bother me at all...I always try and sleep about an hour if I can while I'm on the machine, and if I can sleep that hour on the machine, the rest of the time is not long...and then I try and have the cup of tea and that'll pass another half an hour...there's a lot of little things that you can depend on [to pass the time]. (9/1)

Conversely, in the follow-up interview with David, his experience of leisurely passing the time during dialysis therapy had changed. His narrative signified that the time during treatment was long and drawn out. Regardless of what activity he performed, David was unable to kill time for the entire duration of dialysis.

For instance, he tried to sleep, but inevitably woke up after about an hour. He watched TV, but eventually got bored of this pastime, because he had seen all the films before. While David liked to talk to other patients during haemodialysis therapy, he was blocked by the placement of the dialysis machine. Moreover, he was sometimes situated beside patients that were too tired to talk. This was David's account:

It's [dialysis] boring...you spend three hours stuck on a machine and you're dying to get off...you'd sleep an hour and then when you wake up you're just looking around you...you're watching something on T.V. but you get sick of that too, you've seen all the films already, they're all repeats...now today after you've being here with me, I feel today it's [the time on dialysis] gone before I know it, if you didn't come in, I'd be trying to doze off, go to sleep for five minutes, wake up, look at the clock again to see the time...I try to chat to other patients but everybody seems tired and they're not really in form to talk...and those machines are between the beds as well and you cannot see the person properly...and you can't talk to somebody if you're not looking at them, you're kind of blocked. (9/2)

David's narrative emphasised that he was unable to kill time during haemodialysis therapy. He had nothing to do except watch the clock, while he waited impatiently for the treatment to end. Thus, his account suggested that the time spent waiting was empty and unproductive. The activities he performed to kill time during haemodialysis did not have a significant purpose or outcome. They were only used to get through the empty time spent waiting. Beneath David's account of waiting was the disheartening feeling of wasting time.

Like David, the first interview with Chris, also illuminated the boredom he experienced, while he waited for haemodialysis to end.

He said:

It's good to be able to talk and interact [with other patients] because it definitely passes the time and it kills the time...it makes dialysis easier if you're interacting with other patients...Sometimes, when you're a patient lying there, you get bored, you get so bored...It's good to have interaction between the patients...Maybe patients that do interact should be next to each other, not one at either end [of the ward], people that do interact, have them closer, but sometimes it can be the opposite that's done...Sometimes it's [time] slow and sometimes it's fast...if you're beside someone you talk a lot to, I think it goes faster...If you're talking and doing something, it goes faster, if you're on your own and looking at the ceiling it probably goes slower, it feels slower...the machine blocks patients [from talking]...they [nurses] could have the machine a bit further back. (6/1)

Chris's account confirmed that he had nothing to keep him occupied during haemodialysis therapy. He expressed a yearning to talk to other patients in an effort to kill time. However, the placement of the dialysis machine made it difficult for him to engage in conversation with other patients. In addition, he was occasionally situated

beside patients that tended to sleep during dialysis therapy. Therefore, Chris spent most of his time just waiting for the treatment to end.

In the follow-up interview with Chris, his experience of waiting during haemodialysis therapy had changed. He had commenced a course in computer networks within the last year. Therefore, he was able to kill time working and watching DVDs on his laptop computer. By working on the laptop computer, Chris had been able to fill the time during dialysis therapy more effectively. His account implied that by filling the time, he had subsequently been able to overcome the distressing experience of waiting during haemodialysis therapy.

[L]ately I've been working on the computer, I have CDs I put in, they're like tutorial CDs that I can go through...you forget that you're sitting here on dialysis waiting [to come off], it helps the time go faster I guess...I think I'm doing better with the time than I was, the last time I talked to you, I was having trouble with the time, more I think than now, you just find ways to pass the time. (6/2)

Similarly, in both interviews with Amy, she described her experience of killing time, while she waited for haemodialysis therapy to end. Amy was an insulin dependent diabetic. As a result of her diabetes, she was blind, and had previously had a right lower leg amputation.

In particular, Amy's ability to kill time during the treatment was restricted by her blindness. She was unable to read or watch television during haemodialysis therapy. Therefore, with the exception of sleeping, Amy had nothing to do for the entire duration of the treatment but wait impatiently for it to end.

Well, if I was able to read a book, or even watch the telly, but I have nothing to do, I really don't have anything to pass the time for me, so I just have to lie there and that's it. Sometimes, if I don't have a good night's sleep, I'll have an hour or so of sleep on dialysis in the morning, which does make a big difference, it really does, you don't feel it [time] so long, but I don't usually sleep now. (1/1)

Another participant, John expressed that the time was long while he waited for haemodialysis to end. The televisions rarely worked, which made it difficult for him to kill time. John had re-located to Ireland from the UK about a year before our interview. His account verified that he found it more difficult to kill time during dialysis since he moved to Ireland. He claimed that in the haemodialysis unit in the UK, there was a portable television at each station. Consequently, John was able to watch the programmes he enjoyed during treatment.

John stated:

The time is long [during dialysis]...In the UK, we used to have an individual portable TV, with your own remote, so you could watch what you wanted...and I used to go to dialysis in the evenings from 6 to 10 so it was always when prime time TV were on, so it wasn't too bad because I wasn't doing anything that I wouldn't have been doing if I was at home...it still felt restrictive because you had to sit there but basically if you think about it, I'd have been doing the same thing if I'd been at home...in fact I'd have more choice because my wife wouldn't have control of the remote [laughs]...I don't bother with it [TV] here because the sound is hardly ever on, it's along way off from you, it's never usable to be honest, it might be something in the background, coloured lights but there's no sound really. (14/1)

The ability to freely choose the programmes he liked to watch meant that John was able to leisurely pass the time during haemodialysis therapy. More importantly, it enabled him to adapt a more positive perspective of the treatment.

In addition to the time spent waiting during haemodialysis therapy, the participants also described their experience of waiting before and after the treatment. Their experience of waiting will now be discussed in the following sub theme *Wasting Time*.

4.1.2 SUB THEME - WASTING TIME

The participants indicated that the time consumed when they attended haemodialysis therapy greatly exceeded the actual treatment time. They spent a lot of additional time waiting unnecessarily before and after haemodialysis therapy. Examples of their experiences of waiting included waiting for dialysis machines to become available, waiting for hospital transport to take them to and from treatment, and waiting for doctors to arrive to the unit to attend to them.

While waiting, the participants were unable to participate in their everyday lives and activities. Therefore, they interpreted the experience of waiting, as wasting valuable time out of their everyday lives. The participants had to repeatedly endure the experience of wasting time each time they attended haemodialysis therapy. Therefore, embedded in their accounts were the feelings of irritation, frustration, anger, and despair.

For instance, Harrison, a 66-year-old male described his experience of wasting time, waiting for a haemodialysis machine when he arrived for treatment. Despite having to attend the hospital for treatment three times each week, Harrison continued to work full-time as a community worker. His entire narrative centred on his enthusiasm for the worthwhile role he performed in the community. Therefore, he interpreted the time spent waiting unnecessarily for a dialysis machine, as wasting valuable time, which could be used productively in his daily activities.

In the follow-up interview with Harrison, he recalled a particular incident, where he had to wait an excessively long time for his dialysis machine to become available. Embedded in his account was his frustration and anger toward the nurses on the haemodialysis unit for failing to recognise the distress caused by his experience of repeatedly waiting. Consequently, he decided to complain to the unit manager in an effort to avoid wasting additional time.

Harrison recounted:

I spent an hour and twenty minutes sitting on a chair out in the corridor...I did speak to ____ [unit manager] about it because I was getting fed up of it...I mean we're supposed to be here at half past three and I got on [dialysis] at ten to five...It's just frustrating, I said to ____ [unit manager] "if the dialysis time is ten to five, well tell me it's ten to five, it makes no difference to me, but why have me sitting on a cold corridor" ...I mean I sat there...but I can't do anything sitting in that corridor...I sit there with my legs crossed looking like a fool, that's how I feel and I don't think it's fair to any patient...as I said to ____ [unit manager] "it's organisation, I can't see why you can't draw up a time table for eighty one patients for seven days" ...But you see I think they're too accommodating...if someone comes late, they keep the machine for them, but if you're running a system to help everybody, somebody has to make a sacrifice...I have to travel an hour, surely if I can come on time, these other patients can be on time...I think that's how it should be organised...leave a blank slot on every day, leave a blank bed, so if somebody wants to come late, they can...but it should be for a decent reason, not because somebody is going out for a night and they want to come in early...I saw a fella asking to start [dialysis] on a Friday morning instead of night, they [nurses] told him to come in and they'd see what they could do, and here am I coming at four o'clock and I'm sitting outside in the corridor. (12/2)

It seemed that patients on the haemodialysis unit were allocated a specific dialysis time, but some did not adhere to these times. These patients simply arrived for treatment when it suited them, and were allocated to a dialysis machine by the nurses. This approach to the allocation of dialysis machines caused a cumulative effect throughout the day, which resulted in patients like Harrison having to wait for a machine to become available.

In a similar account, Alex also recalled his experience of waiting excessively for a dialysis machine to become available when he would present for treatment. His account was taken from his follow-up interview. At the time, he had recently received a kidney transplant. While Alex was on haemodialysis therapy, he continued to work as an electrician. He drove himself to and from haemodialysis therapy, which took an hour each way. Therefore, on dialysis days, Alex had to finish work early to get to the hospital at the appropriate time for his treatment. However, his account implied that

there were occasions when he would arrive to the unit and have to wait for up to two hours for a machine to become available.

Alex recalled:

At times you could be waiting anything from an hour to two hours, it depended, it made it [dialysis] that much harder because it was an hours drive up and an hours drive back, that was two hours and you have four hours on the machine, that was six hours, so another two hours waiting just added to it as well, so it averaged about seven to eight hours a day to get your dialysis, to get there and back...so there was waiting involved, and once you get on [the machine], you were waiting to get off, so it's all waiting...It's kind of frustrating really, it's hard to go in and sit for two hours and think half your dialysis could be done when you haven't even started...it's just more frustrating than anything...There was no one to say why they delayed us, it just seemed to be a normal part of life in dialysis, if someone came in a few minutes early, there's a very strong possibility that they got in ahead of you and they might actually have your bed gone...it's hard to pull them out then, and that did actually happen a good bit, someone might come in for whatever reason and if the bed was there, they [nurses] tended to put them on and dialyse them. (3/2)

Like Harrison, Alex's narrative also verified that the nurses effectively overlooked his distressing experience of wasting time, having to wait for a dialysis machine. He said the nurses would put patients on machines, even if they arrived outside of their allocated time. Therefore, despite arriving promptly for treatment, Alex was still left waiting for a machine. His account conveyed how the experience of waiting unnecessarily for a haemodialysis machine simply devoured more time out of his everyday life. Therefore, beneath Alex's account, was the frustrating feeling of wasting time.

Gloria also described her experience of waiting for a dialysis machine to become available when she attended dialysis therapy. Gloria indicated that there were times when the nurses were so busy that patients would have to wait for a machine to become available. Like Alex, her account implied that the time spent waiting merely consumed more time out of her everyday life. Gloria's description of "just hanging around waiting" exemplified that she had nothing to do while she waited. Thus, embedded in her account was the irritating feeling of wasting valuable time out of her everyday life.

There was a time when they [nurses] were very busy and there were ten patients all coming in together at the one time, and that meant that you had three quarters of an hour to wait before you got on the machine...you were just hanging around waiting...I know I'm contradicting myself when I said before that I don't mind hanging around if I'm not on the machine,³¹ but it's different when your coming off dialysis...but before it [dialysis], you're waiting to go on it and you're thinking, "oh another half an hour, that'll be a half hour later getting off than I thought I'd be"...it eats more time...you just want to get in, and get it over and out of the way as fast as you can. (11/1)

Correspondingly, Amy also recounted her experience of wasting time waiting for a haemodialysis machine to become available. As mentioned previously, Amy was an insulin dependent diabetic and was blind. She also had a right lower leg amputation in the past because of recurrent diabetic foot ulcers.

At the time of the follow-up interview, Amy had been on haemodialysis therapy for two years. She said:

Well it's great to come in at this time [6am], you just walk in and go on the machine, because you're long enough in here without having to wait...and that can't be helped either because when you're on the machine, you don't know what's going to happen...like I've been delayed a few times trying to stop the blood [bleeding from fistula after dialysis], but of course somebody has to wait, and it's always because something is happening to someone or another...It's terrible, it's really terrible [to have to wait for a dialysis machine] and I am quite patient but really it used to happen day after day, at least a half an hour...and a half an hour waiting feels like ages, but it was often the hour and more than an hour...but some girl had a transplant [and left the unit], she used to come in at six, so I asked to come in at six instead, and it's a way better. (1/2)

Amy's narrative indicated that the time passed slowly, while she waited impatiently for a dialysis machine to become available. She implied that dialysis therapy consumed enough time out of her life, without having to waste more time waiting for a machine. Therefore, to avoid this unnecessary waiting, Amy had recently taken a dialysis time of six o' clock in the morning. Arriving to the unit at this time ensured that Amy avoided wasting valuable time, waiting unnecessarily for a haemodialysis machine to become available. Consequently, her experience of attending the treatment has improved.

³¹ See page 137 for Gloria's previous description of killing time during haemodialysis where she describes her experience of waiting after haemodialysis is over.

Elena also recalled her experience of wasting time, while she waited for doctors to attend to her during haemodialysis therapy. Elena had recently begun to use her AVF during haemodialysis therapy. However, prior to using her fistula, she relied on a central venous catheter (CVC) to gain access to her bloodstream during treatment.

Elena experienced recurrent clotting and poor blood flow in her CVC, which required frequent administration of a thrombolytic agent before and after haemodialysis therapy. In order to have the thrombolytic agent inserted into her CVC, Elena had to wait for a doctor to arrive to the dialysis unit to administer it before and after treatment. In addition, she had to wait for an hour to allow the clot(s) to dissolve before dialysis could commence.

This was Elena's account:

The [dialysis] line wouldn't work...it was so annoying all the waiting, you'd have to wait for the doctor to come and put something down to clear the line and then you'd have to wait another hour to let it work...there's so much wasted time...As well, I have to come from [patients home], which takes an hour and a quarter to get here, then when I'd get here, the [dialysis] line would pack up in the first hour and I'd have to wait for the doctor, which could take another half an hour and it has taken longer...at the end of dialysis again I would have to wait for the doctor to come back and put more stuff into the line, so it works the next time...By the time I'd go home I would be absolutely exhausted ...I sent a letter of complaint to the hospital at one stage because it was really frustrating, you get angry. (10/1)

Within Elena's account was her anger and frustration towards the healthcare team for ignoring her distressing experience of wasting time. Hence, she decided to send a letter of complaint to the management of the hospital in an effort to address the problem.

In the follow-up interview with David, he described his experience of wasting time, while he waited for hospital transport to take him home after his treatment. David availed of a taxi, which was organised by the hospital, to take him to and from the dialysis unit. He shared the hospital taxi with another patient on haemodialysis, called John.

David's treatment time was three hours, while John's was four hours. Consequently, David had to wait for at least an extra hour after he finished his treatment before the hospital taxi would take them both home. John had an AVF, which sometimes took a while to stop bleeding after dialysis. When this problem occurred, David's waiting time was significantly increased.

On the day of the follow-up interview with David, he had also been waiting for one hour and twenty minutes for a haemodialysis machine to become available. This additional time spent waiting, merely contributed to the distressing experience of wasting time illustrated within his account.

David said:

I live fifty miles away from here [dialysis unit], and it takes over an hour to get in here in the morning, and the same to get home in the evening...and then I share the [hospital] taxi with another patient and I could be waiting for him...I only do three hours on dialysis and the other guy does four, so I have to wait an hour for him...so sometimes I'd be off [dialysis] for nearly two hours before I'd get home...You get off the machine, you go out to the day room, you sit there for an hour, then if it's hard to stop the bleeding [from John's AVF], he could be an extra half hour, and if he didn't feel well, he could be there for two hours, and you're sitting around waiting, waiting...That is very annoying, you run out of patience, that's my problem...I came in this morning at about twenty minutes to twelve...I didn't get on the machine until one o'clock, so that's another hour gone, it's really a drag, the time is passing by and you're wasting time for nothing...The whole thing is wasting time...You're wasting your own time...So if you had home dialysis [peritoneal dialysis], you wouldn't be waiting around, and you wouldn't be hanging about in this place...it would make a big difference, because I'm wasting a whole day. (9/2)

David's narrative implied that the time spent waiting before and after haemodialysis therapy held him back from his everyday activities, and was subsequently interpreted as wasting valuable time out of his life. Indeed, the frustration and anger, which accompanied his experience of waiting, were evident within his account. David's account signified that his experience of waiting excessively for hospital taxis was not going to be rectified. Therefore, to avoid this pointless waste of his time, he was seriously considering changing from haemodialysis therapy to having peritoneal dialysis in his own home.

Like David, Nancy also recalled her experience of wasting time, when she waited for a hospital taxi to take her home after haemodialysis therapy. In the follow-up interview with Nancy, she had recently received a kidney transplant after being on dialysis for four years. She signified that when she attended haemodialysis therapy, she used to travel to the unit in a hospital taxi with another patient called Mark. Therefore, when Mark had complications after dialysis therapy, she would have to wait for him to recover before the taxi would take them both home. Conversely, if Nancy had problems, Mark would have to wait.

Nancy's account exemplified the impatience and resentment she experienced because of having to wait for Mark after she finished. Moreover, it also illustrated the stress and pressure she experienced when she was the cause of the delay.

Nancy recounted:

I was sharing a taxi with Mark [another patient] and if he had a problem, I had to wait, if I had a problem, he had to wait, and there was a lot of problems with bleeding [from AVFs], and Mark had trouble with his heartbeat...So not only are you dealing with your own problems but you're thinking "I hope they don't call the doctor for Mark, please Mark don't be sick"...and you feel bad because you've had these bleeders, you've had these cramps, they're all problems dialysis patients have but Mark is getting them, and you're thinking "I'm going to be late tonight"...And if you have problems, you get stressed out and you're thinking "he's [Mark] waiting in the taxi for me", so you were putting more pressure on yourself, then you're apologising when you get into the taxi, and you're still sick. (16/2)

The narrative account of Carl also characterised the experience of waiting as wasting time. In the follow-up interview with Carl, he said that when he initially started haemodialysis therapy, he had availed of a hospital taxi to take him to and from treatment. However, the taxi driver would call to collect him hours in advance of his allocated treatment time. This frequently resulted in Carl having to wait up to three hours before a dialysis machine became available.

Carl also shared a hospital taxi with another patient, and had to wait for this patient to complete her treatment before the taxi would take them both home. Because of the excessive waiting, Carl was wasting an entire day just to attend haemodialysis therapy. This subsequently prevented him from working full-time.

As a result of being unable to work full-time, Carl decided to drive himself to and from the unit. By organising his own transport, Carl had been able to overcome the distressing experience of wasting time, waiting unnecessarily before and after haemodialysis therapy. More importantly, he had been able to return to work on a full-time basis.

I was coming in here at twelve o'clock in the day and the whole day was gone...I was getting picked up by a [hospital] taxi...so I'm driving myself now because it just puts up the time waiting for a taxi...I'm so far away, I live forty miles away and he [taxi driver] used to come two hours, maybe two and a half to three hours before my dialysis time, and you could be an hour waiting in the evening before he used to come to pick us up...I was travelling with another woman as well, so the whole day was gone, you could do nothing...It's grand now, I can come in here in the evening and work during the day and you'd be alright for work then again in the morning...[I used to be] sitting up there waiting, waiting up there in the waiting room, because we'd different times, me and the other woman that was travelling with me...I was only on three and a half hours and she was on four hours, and she was an old woman and it [dialysis] affected her a little bit, she wasn't just able to get up and walk out the door after it, she had to rest for a while, so he [taxi driver] always had time laid out to give her a bit of recovery time as well before he'd come...so it was long...I could be off [the machine] for an hour and a half before he [taxi driver] used to come...where now you can just go when you get off [the machine]...it gives you more freedom and more independence to come and go, and you're not waiting for taxis. (5/2)

Similarly, Jeff recalled his experience of wasting time, while he waited for a hospital taxi to take him to the dialysis unit for treatment. Like Carl, when Jeff initially started haemodialysis therapy, he also availed of a taxi to take him to and from the hospital. However, the taxi driver did not arrive at the same time each evening. Therefore, Jeff was wasting time, waiting for him to arrive.

You were ready for an hour expecting someone to pick you up say at half three, and half three would come and no one would arrive...it could be four o'clock and the taxi would just pull up then and he [taxi driver] would never say why he was late...if it suited him [taxi driver], he could come at three o'clock, before you'd be even ready, it's whatever suited him really, I used to be late here for dialysis...I'm meant to be here at five o'clock, and it was often half five or quarter to six before I was here, so that was very frustrating...that's why I started to drive and I'm still driving now and I wouldn't change it. (13/2)

Both Jeff and Carl signified that they were forced to organise their own transport to and from haemodialysis, to overcome the experience of wasting time waiting for taxis.

4.1.3 DISCUSSION OF THEME

It is suggested that time played a key role in the participants' experience of waiting, presented in the theme *Lost Time*.³² Like the participants' accounts, the existing literature highlighted how the time-consuming nature of haemodialysis therapy created disruptions in the person's life (Nagle, 1998; Hagren et al., 2001; Heiwe, Clyne & Dahlgren, 2003; Hagren et al., 2005). However, in contrast to this literature, it was not the linear, succession of "nows" of clock time that was significant in the participants' experience of waiting. Instead it seemed that the participants' experience of waiting, described in the theme *Lost Time* created a disruption to the four defining features of world-time.

If we recall, Heidegger suggested that world-time was Dasein's qualitative experience of time in its everyday involvements in the world. In particular, it was the time that contained the everyday activities performed by Dasein.³³ There were four defining features of world-time called significance, datability, spannedness, and publicness. The participants' experience of waiting, described in the sub themes *Killing Time* and *Wasting Time* appeared to create a disruption to the four defining features of world-time. The following discussion will illustrate how this disruption might have occurred.

According to Heidegger (1962), world-time was significant because we always understood the "now" as either the right or wrong time to do certain things.³⁴ The tasks we performed in world-time were significant because they were based on the future of ordinary temporality. We performed tasks in world-time in-order-to project forward into some possibility in the future. Therefore, it was our possibilities in the future, which determined whether it was the right or wrong time to perform certain tasks or activities.

³² This theme will also be discussed in relation to a broader body of literature (specifically the work of Janice Morse) in Chapter 5: *Discussion of the Findings*.

³³ See page 97 for the previous discussion on Heidegger's analysis of world-time.

³⁴ See page 100 for the previous discussion on the significance of world-time.

The participants' descriptions of waiting, described in the theme *Lost Time* suggested that the time spent waiting was unrelated to their everyday lives. It did not contain the everyday activities and tasks associated with world-time. The participants had nothing productive to do while they waited. Therefore, the time spent waiting was effectively empty.

For instance, in the sub theme *Killing Time*, the participants described how the activities they used to kill time during haemodialysis therapy, were not performed in-order-to project into some possibility or goal in the future. These activities did not have a significant outcome or purpose. They were merely used for the sole purpose of killing time until haemodialysis therapy ended.³⁵ Correspondingly, in the sub theme *Wasting Time*, the participants described their experience of waiting needlessly before and after haemodialysis therapy. The time spent waiting held the participants back from their everyday activities and was interpreted as wasted time.³⁶

These features of the participants' experience of waiting, contained in the sub themes *Killing Time* and *Wasting Time* indicated that they were not acting in world-time in-order-to project forward into possibilities in the future. Consequently, these findings implied that the participants' experience of waiting created a disruption to the significance of world-time. The intermittent nature of haemodialysis therapy meant the participants had to repeatedly endure this disruption to the significance of world-time each week.

Dasein dated events in its everyday involvements in the world because the events had significance. Therefore, datability was inextricably linked to significance and implied that the experience of time was dated by events.³⁷ Dasein's experience of the "now" of world-time was experienced as a time when a significant event occurred. Datability only materialised if the person was able to engage in significant events in the everydayness of world-time. As mentioned above, the participants' experience of wasting time and killing time signified a disruption to the significance of world-time. Hence, it is

³⁵ For example, see the accounts of Ali (p134), Nancy (p135), David (p141), Chris (p141).

³⁶ For example, see the accounts of Harrison (p145), Gloria (p146), Elena (p148), David (p149).

³⁷ See page 100 for previous discussion on the datability of world-time.

proposed that the disruption to significance subsequently created a disruption to the datability of world-time.

World-time was spanned because it was embedded in the originary present.³⁸ The originary present spanned from the originary future to the originary past. This spannedness was retained in world-time. Therefore, the “now” of world-time extended, or spanned from the “no-longer-now” (before) to the “not-yet-now” (after). The spannedness of world-time was also retained in the temporality of circumspective concern.

Recall how, in the temporality of circumspective concern, Dasein performed tasks in the “now”, by “retaining” the necessary background experience, and “awaiting” the completion of the task.³⁹ Therefore, the actual performance of the task spanned from the retaining to the awaiting of the task. It was because the world-time “now” spanned or extended from the before to the after, that the task spanned from the retaining to the awaiting in the temporality of circumspective concern. Therefore, the spanned “now” of world-time was constituted by a task, and subsequently lasted for the duration of the task.

The participants’ descriptions of waiting contained in the theme *Lost Time*, illustrated that the “now” spent waiting was not constituted by a purposeful task or activity. For instance, in the sub theme *Killing Time*, the participants described how the activities they used to kill time during haemodialysis therapy did not have a productive outcome or purpose. They were merely used to occupy them until the treatment ended. Therefore, these activities did not fill the entire duration of haemodialysis therapy and the participants endured empty time, while they waited for the treatment to end.⁴⁰

Likewise, the participants’ accounts of waiting contained in the sub theme *Wasting Time* conveyed how the time spent waiting held them back from their everyday activities. They did nothing fruitful while they waited needlessly before and after haemodialysis therapy. Thus, they described the experience of waiting, as wasting

³⁸ See page 101 for the previous discussion on the spannedness of world-time.

³⁹ See page 98 for the previous discussion on the temporality of circumspective concern.

⁴⁰ For example, see the accounts of Ali (p134), Nancy (p135), David (p141), Chris (p141).

time.⁴¹ The participants' experience of killing time and wasting time confirmed that the "now" spent waiting was not constituted by a task or activity. This implied that their experience of waiting represented a disruption to the spannedness of world-time.

By creating a disruption to the spannedness of world-time, it is proposed that the participants' experience of waiting also created a disruption to the spannedness of originary temporality. If we recall, world-time constituted the originary present.⁴² Through world-time, the originary present provided originary temporality with its spannedness. The person performed tasks and activities in world-time (i.e. originary present) based on his/her attunements from the past, to project forward into possibilities in the originary future. Therefore, if there was a disruption to the spannedness of world-time, there was subsequently a disruption to the spannedness of originary temporality.

The "now" of world-time was public, which implied that we collectively understood what now meant.⁴³ The publicness of the "now" of world-time ensured that we were able to collectively coordinate our tasks, activities, and practices on a daily basis. According to Heidegger (1962), world-time was public because originary temporality was public. "Being-with-others" was an essential structure of our existence and simultaneously of originary temporality. Dasein was thrown into the world along with others. Therefore, being in the world was social in nature.

It is suggested, that the participants' descriptions of waiting, illustrated in the theme *Lost Time* characterised a disruption to the publicness of world-time. In particular, the participants' accounts of waiting, described in the sub theme *Killing Time* showed that the time spent waiting during haemodialysis therapy, was not a time for being-with-others. Nor was it a time for collectively co-ordinating activities and tasks with other people.

For instance, some participants specifically expressed their desire to talk to other patients in an effort to kill time during haemodialysis therapy. However, the layout and organisation of the dialysis unit did not facilitate communication between patients.

⁴¹ For example, see the accounts of Harrison (p145), Gloria (p146), Elena (p148), David (p149).

⁴² See page 97 for previous discussion on world-time.

⁴³ See page 101 for the previous discussion on the publicness of world-time.

Moreover the level of nurse-patient communication rarely extended beyond a superficial level.⁴⁴ Hence, the participants remained largely isolated during the treatment.⁴⁵ These aspects of the participants' accounts of killing time seemed to illustrate a disruption to the publicness of world-time.

The participants' experience of waiting, described in the sub theme *Wasting Time* also characterised a disruption to the publicness of world-time. The participants indicated that they wasted a lot of time waiting unnecessarily before and after haemodialysis therapy. They provided accounts of waiting for haemodialysis machines to become available, waiting for hospital taxis to take them to and from the hospital, and waiting for doctors to attend to them during treatment.⁴⁶

As mentioned previously, the publicness of the "now" of world-time ensured that we were able to collectively coordinate our tasks, activities, and practices on a daily basis. However, the participants' accounts of wasting time confirmed that "now" did not collectively mean the same thing to the participants, as it did to the staff working in the healthcare system. As a result, the participants spent a lot of time waiting unnecessarily before and after haemodialysis therapy.

For example, the participants were given a specific time to attend haemodialysis therapy. However, when they arrived at that specific time, their machine was unavailable. The lack of a structured and coordinated approach to the allocation of haemodialysis machines on the unit meant the nurses' understanding of "now" did not correspond with the participants' understanding of "now". Hence, the participants were left waiting around until a haemodialysis machine eventually became available.⁴⁷

The participants who used the hospital taxi service also described their experience of waiting unnecessarily when they attended haemodialysis therapy. They stated that the hospital taxi drivers were supposed to arrive at a specific time to take them for haemodialysis therapy. However, it seemed "now" did not collectively mean the same

⁴⁴ The superficial level of communication will be discussed in the upcoming theme titled *Communicating with nurses: Myth versus Reality*.

⁴⁵ For example, see the accounts of Ali (p134), David (p141), and Chris (p141).

⁴⁶ See page 144 for the sub theme *Wasting Time*.

⁴⁷ For example, see the accounts of Harrison (p145), Alex (p146), Gloria (p146), Amy (p147).

thing to the participants and the taxi drivers. Therefore, the drivers would arrive either too early or too late to take the participants to dialysis. If the driver arrived early, the participant had to wait for a machine when they got to the unit. Conversely, if the driver arrived late, the participant would be left waiting at home.⁴⁸

By using the publicness of the “now” to collectively coordinate our tasks and activities on a daily basis ensured that a breakdown in our everyday activities was avoided (Heidegger, 1962). However, the valuable time wasted, as a result of waiting unnecessarily for dialysis machines, taxi drivers, and doctors made it difficult for the participants to coordinate their everyday activities and lives around haemodialysis therapy. Consequently, it is suggested that the participants’ experience of waiting, described in the sub theme *Wasting Time* created a disruption to the publicness of world-time.

The above discussion highlighted how the participants’ experience of waiting, contained in the theme *Lost Time* may have created a disruption to the four features of world-time. The defining features of originary temporality were retained in world-time. Indeed, world-time actually constituted the originary present. It is for this reason, that a disruption in world-time may have precipitated a disruption to originary temporality. The disruption to world-time and originary temporality caused by the participants’ experience of waiting symbolised various characteristics of Heidegger’s (1995) description of boredom.

According to Heidegger (1962), boredom was a fundamental existential mood, which highlighted the finitude of one’s existence.⁴⁹ He identified three forms of boredom, which ranged from the most superficial to the most profound. The third form of boredom was the most profound because it disclosed Dasein’s finite existence. Therefore, the third form of boredom was the origin of the other two forms of boredom. Heidegger (1995) said that we all had an uneasy awareness of the experience of profound boredom within ourselves. It was this awareness, which alerted us to escape from the first and second forms of boredom.

⁴⁸ For example, see the accounts of Carl (p151) & Jeff (p151).

⁴⁹ See page 125 for Heidegger’s analysis of boredom as an existential mood.

The unpleasant awareness of our finite existence, which was most profound in the third form of boredom, was also retained in both the first and second forms of boredom. This awareness was superficial in the first form of boredom, but more intense in the second form. Thus, the second form of boredom was described as being more profound or intense than the first. By fleeing from the first and second forms of boredom, we were ultimately trying to avoid oscillating into the third and most profound form of boredom. However, if for some reason, we were unable to flee from either the first or second form of boredom, we were drawn into profound boredom, and were subsequently confronted with the finitude of our existence.

It is suggested that the participants' relentless experience of waiting, described in the theme *Lost Time* meant they were unable to flee from the first and second form of boredom. Hence, they were drawn into the third and most profound form of boredom, described by Heidegger (1995). In the following discussion, the three forms of boredom will be analysed in relation to the theme *Lost Time*.

4.1.3.1 The First Form of Boredom

According to Heidegger (1995), the first form of boredom involved “becoming bored by something” (p78). For example, we may become bored by certain things, such as a book, a play, or a prolonged wait for a flight, bus, or train. Time dragged in this type of boredom because we were bound in a situation, which was limited in extrinsic stimulation (Heidegger, 1995). Therefore, the cause of boredom came from outside and was obvious (Aho, 2007).

Heidegger (1995) stated that when we were forced to wait in a particular situation, we experienced the first form of boredom. The theme *Lost Time* highlighted that the participants had to repeatedly endure the experience of waiting each time they attended haemodialysis therapy.⁵⁰ Patients with ESRD require haemodialysis therapy in order to survive. Therefore, the participants had no choice but to endure the distressing experience of waiting each time they attended the haemodialysis unit for treatment.

⁵⁰ See page 132 for the theme *Lost Time*.

In the first form of boredom, the time became long and seemed to pass slowly or drag (Heidegger, 1995). Therefore, the person tried to do things in an effort pass the time and get rid of the boredom. According to Heidegger (1995), “passing the time is a driving away of boredom that drives time on”(p93).

The participants’ narratives in the sub theme *Killing Time* conveyed that time dragged during haemodialysis therapy. The strategies they used were insufficient to kill time for the entire duration of haemodialysis therapy. Hence, they spent a large proportion of time merely waiting for the treatment to end.⁵¹

The participants described their experience of watching the clock, while they waited for the treatment to end.⁵² The impatience, uneasiness, irritation, and frustration were expressed within their accounts of killing time. The participants’ predominant focus on clock time was also illustrated in their accounts of wasting time before and after dialysis therapy.⁵³

According to Heidegger (1995), in the first form of boredom the person watched the clock. However, watching the clock was not a way or means of passing the time, such as reading a book, or watching television. Rather, watching the clock was a sign that our efforts to pass the time were not successful. Therefore, boredom continued to torment us, and our impatience and uneasiness verified this fact (Heidegger, 1995). By watching the clock, we were trying to gauge how much time was left before the wait was finally over. As Heidegger (1995) indicated, “It is not a matter of simply spending time but of killing it, of making it pass more quickly” (p97).

Heidegger (1995) described two structural moments or features of the first form of boredom: *being held in limbo*, and *being left empty*. In the first form of boredom, we were held in limbo by time as it dragged for a particular duration. For instance, when we waited for the train, we were held in limbo by the dragging of time until the train

⁵¹ For example, see the accounts of Ali (p134), Nancy (p135), Alex (p138), and Donna (p139).

⁵² For example, see the accounts of Gloria (p137), Donna (p139), David (p141), and Elena (p140).

⁵³ For example, see the accounts of Harrison (p145), Alex (p146), Gloria (p146).

arrived. Likewise, while the participants waited for haemodialysis to end, they were held in limbo by the dragging of time.

When Heidegger (1995) claimed that we were held in limbo by time as it dragged in the first form of boredom, he meant that we were held back from the everyday activities, which we normally performed in world-time. If we recall, world-time referred to the person's qualitative experience of time in its everyday involvements in the world. In particular, it was the time that contained the everyday activities performed by the person. World-time actually constituted the originary present, and was thus embedded in originary temporality.

The person performed activities in world-time (originary present) in-order-to project forward into possibilities in the originary future. Therefore, the everyday activities performed by the person in world-time were full, in that they had a specific purpose or outcome (Heidegger, 1995). The person was fully occupied with these activities and absorbed him/herself within them on a daily basis.

Conversely, the things and activities used by the person to kill time when trying to drive away the first form of boredom, were not the same as the absorbed, everyday activities performed in world-time (Heidegger, 1995). The person did not really have a vested interest in the activities s/he did to pass the time, nor was s/he focused on the outcome of the activity. Hence, the activities used by the person to pass the time were essentially empty. They were merely used as a way to keep the person occupied. Therefore, when the person was held in limbo by time as it dragged in the first form of boredom, s/he was also left empty by the things and activities used to pass the time (Heidegger, 1995).

The participants' accounts in my study signified that the activities they used to kill time during haemodialysis therapy were not the same as the absorbed, activities they performed in their everyday lives. The activities they used to kill time did not have a specific outcome or purpose. They were simply performed by the participants to pass the time during the treatment. As a result, it seemed that the participants were left empty by these activities. Indeed, their accounts indicated that the activities they performed did

not effectively kill time for the entire duration of haemodialysis therapy.⁵⁴ Therefore, because of being held in limbo by the dragging of time, the participants were also left empty by the activities they used to kill time, while they waited for haemodialysis to end.

Heidegger (1995) claimed that particular things or events have their particular time. This was previously mentioned in the discussion on world-time.⁵⁵ If we recall, significance was one of the defining features of world-time. World-time was significant because the person always understood the “now” as either the right time or wrong time to do certain things. Therefore, the “nows” of world-time were significant because they were either appropriate or inappropriate for certain activities. For example, “now” while I am doing this work on the computer, is not the right time for watching television.

Heidegger (1995) stated that the first form of boredom occurred when the person exceeded the appropriate time for a particular thing. When the person exceeded the time that was appropriate for a specific thing, s/he was held in limbo and left empty. For instance, when our train was delayed, we exceeded the time that we expected to be in the train station. Until the train arrived, the train station offered us nothing. As a result, the train station both held us in limbo and left us empty until the train arrived.

The participants’ accounts of waiting, presented in the sub theme *Wasting Time* highlighted that they spent a large proportion of time waiting unnecessarily before and after haemodialysis therapy.⁵⁶ As a result, the time spent in the dialysis unit greatly exceeded the actual treatment time. This additional time spent waiting held the participants back from their everyday lives and activities. Consequently, the haemodialysis unit offered them nothing, and essentially left them empty, while they waited before and after the treatment.

The first form of boredom, advanced by Heidegger was a transient form of boredom (Aho, 2007). As soon as the train arrived, we escaped the boredom of the railway station. However, the participants’ descriptions of waiting, described in the theme *Lost*

⁵⁴ For example, see the accounts of Nancy (p135), Donna (p139), Elena (p140), and David (p141).

⁵⁵ See page 97 for the discussion on world-time.

⁵⁶ For example, see the accounts of Harrison (p145), David (p149), Elena (p148), and Nancy (p150).

Time suggested that their experience of waiting was not transient. They had to repeatedly endure the distressing experience of waiting each time they attended the hospital for haemodialysis therapy. As a result, they were continuously held back from their everyday activities, and subsequently endured a disruption to world-time.

The participants' experience of repeatedly waiting when they attended haemodialysis therapy implied they were unable to flee from the first form of boredom. Therefore, it is proposed that the participants oscillated into the second, and more profound form of boredom, described by Heidegger (1995).

4.1.3.2 The Second Form of Boredom

Heidegger (1995) stated that the second form of boredom was more profound than the first. It involved "being bored *with* something" (p106). However, unlike the first form of boredom, it was something indeterminate and unfamiliar, which seemed to cause the second form of boredom (Heidegger, 1995). The something indeterminate and unfamiliar that caused the second form of boredom was the standing of world-time. Therefore, in the second form of boredom, we were held in limbo by the standing of world-time (Heidegger, 1995).

According to Heidegger (1995) our passing the time was somehow repressed in the second form of boredom. For some reason, we were not able to move freely and get into activities like we did to pass the time in the first form of boredom (Heidegger, 1995). Heidegger (1995) used the example of being invited somewhere for the evening, to exemplify how our passing the time could be suppressed in the second form of boredom. For instance, when we were at the evening invitation, our ability to freely pass the time e.g. by pacing up and down, reading a book, watching television, was suppressed because of the social rules of politeness, which governed the situation (Heidegger, 1995).

The participants' descriptions of waiting, presented in the sub theme *Killing Time* highlighted how their efforts to kill time were suppressed during haemodialysis

therapy.⁵⁷ It is suggested that this suppression culminated in the second form of boredom, described by Heidegger (1995). As previously mentioned, world-time referred to the irreversible, sequence of times called “nows”, where the present was the “now”, the past was the “no-longer-now” and the future was the “not-yet-now”. It was the time that contained the activities performed by the person in his/her everyday involvements in the world.⁵⁸ Indeed, these activities provided world time with its irreversible sequence or flow. However, when these activities stopped, the flowing of world-time also stopped and it subsequently came to a stand.

According to Heidegger (1995), when world-time came to a stand, the “now” was not eliminated. Rather, it did not have the possibility of a transition from a “not-yet-now” to a “no-longer-now”. Hence, for the duration of time that the person was unable to engage in his/her everyday activities, the present “now” was merely static. The person was forced to endure the present “now” of world-time, cut off or unbounded from the “not-yet-now” and the “no-longer-now” (Heidegger, 1995).

Heidegger (1995) used the example of the evening invitation to highlight how world-time came to a stand in the second form of boredom. He said that while the person attended the evening invitation, the activities s/he normally performed in world-time were suspended. Therefore, the irreversible flow of world-time subsequently came to a stand for the duration of the evening.

From Heidegger’s (1995) perspective, in our everyday understanding of time, be it world-time or ordinary (clock) time, time flowed. Therefore, the standing of world-time caused it to become something unfamiliar and indeterminate. It was this standing of world-time, as distinct from flowing, that was the unfamiliar and indeterminate “something” that bored the person in the second form of boredom.

As previously discussed, the participants’ experience of waiting, described in the theme *Lost Time* created a disruption to the four features of world-time.⁵⁹ It is suggested, that the disruption in world-time, caused by the participants’ experience of waiting, may

⁵⁷ For example, see the accounts of Ali (p134), Alex (p138), Nancy (p135), Donna (p139).

⁵⁸ See page 97 for the previous discussion on world-time.

⁵⁹ See page 152 for the previous discussion on the disruption to the four features of world-time created by the participants’ experience of waiting, described in the sub themes *Killing Time* and *Wasting Time*.

have brought world-time to a stand. It is subsequently proposed that the standing of world-time culminated in the second form of boredom, described by Heidegger (1995).

Heidegger (1995) used the example of the evening invitation to illuminate the transient nature of the second form of boredom. He emphasised that the boredom experienced during the evening only lasted for the duration of time we were there. Once the evening was over, we would be able to flee or escape the boredom. However, if for some reason the person was unable to flee the second form of boredom, s/he progressed into the third and most profound form of boredom (Heidegger, 1995).

The participants in the study had to repeatedly endure the experience of waiting each time they attended haemodialysis therapy. This implied that they were unable to overcome the standing of world-time, and were subsequently unable to flee or escape from the second form of boredom. Therefore, it is proposed that the participants' inability to escape from the second form of boredom may have caused them to advance into the third and most profound form of boredom, described by Heidegger (1995).

4.1.3.3 The Third Form of Boredom

Heidegger (1995) claimed that the third form of boredom was the most profound kind of boredom. He said "profound boredom bores when we say, or better, whenever we silently know, that *it is boring for one*" (p134).

In the third form of boredom, Dasein was held in limbo by the suspension of time. However, the time that related to profound boredom was different from our normal, everyday understanding of time, as ordinary (clock) or world-time. Instead Heidegger (1995) claimed that in profound boredom "time entrances [*bannt*] Dasein, not as the time which has remained standing as distinct from flowing, but rather the *time beyond such flowing and its standing*, the time which in each case *Dasein itself as a whole* is" (p147). The third and most profound form of boredom was caused by the suspension of originary temporality (Haar, 1999). Therefore, the time Heidegger referred to in the quote above was the threefold structure of originary temporality.

In order to understand the third form of boredom, we must replace our understanding of time as ordinary or world-time, with Heidegger's (1962) notion of originary temporality.⁶⁰ If we recall, originary temporality was composed of an "ecstatic" unity that consisted of the future, past, and present. We acted in the originary present, based on our affectedness from the originary past, to project forward into possibilities in the originary future. In the third, and most profound form of boredom, originary temporality was suspended or stopped. Profound boredom took apart the synthesis of originary temporality (Haar, 1999). As a result, the past and future became detached from the present ecstases of originary temporality.

It seemed that the participants' inability to flee the first and second forms of boredom caused them to progress into the third form of boredom, described by Heidegger (1995). As previously highlighted, the participants' experience of waiting, described in the theme *Lost Time* created a disruption to world-time.⁶¹ Now world-time was embedded within the unified structure of originary temporality, and constituted the present ecstases of originary temporality. The person performed his/her everyday activities and actions in world-time (the originary present) to project forward into possibilities in the originary future. Therefore, a disruption to world-time subsequently culminated in a disruption to originary temporality.

When world-time was disrupted, the person was no longer acting in the originary present to project forward into possibilities in the future. Therefore, originary temporality was also suspended or stopped. It is proposed, that the disruption to world-time created by the participants' experience of persistently waiting, resulted in a disruption in the threefold structure of originary temporality. This caused the suspension of originary temporality, which culminated in profound boredom.

In profound boredom, we were held in limbo by the suspension of originary temporality (Heidegger, 1995). Heidegger indicated that when we were held in limbo by the suspension of originary temporality, we were held back from our own possibilities in life; we were held back from our past and future; and finally we were held back from

⁶⁰ Refer to page 93 for the previous discussion on Heidegger's notion of originary temporality.

⁶¹ See page 152 for the discussion on the disruption to world-time created by the participants' experience of repeatedly waiting when they attended haemodialysis therapy.

the time we were familiar with in our everyday involvements in the world i.e. world-time (Haar, 1999).

As a result of being held in limbo by the suspension of originary temporality, we were forced to recognise and endure empty time (Haar, 1999). When originary temporality was suspended, the past and future became isolated from the originary present. This did not mean that the past and future disappeared, or were permanently removed. It simply implied that their defining features within the unified structure of originary temporality were suspended (Haar, 1999).

The disintegration in the ecstatic unity of originary temporality forced the present ecstases to stretch and lengthen itself to fill the entire time horizon (Hoffman, 2005). In other words, the present extended to fill the void left by the other two ecstases. However, without the defining features of the originary past and future, the extended present also lost its defining features. Therefore, it became characterised by inaction, and the person was forced to recognise and endure empty time (Haar, 1999). The empty present led to nothing but a repetition of the same present (Haar, 1999).

Because time was essentially empty, everything seemed empty when we experienced profound boredom. The empty time of boredom was not related to our past or future. Therefore, while we remained trapped in this empty time, everything seemed to be without value and indifferent to us (Haar, 1999).

The participants' descriptions of waiting, presented in the theme *Lost Time* suggested they were held in limbo by the suspension of originary temporality. For instance, the participants' descriptions of *Killing Time* and *Wasting Time* implied that they were unable to do anything productive while they waited relentlessly. The time spent waiting was unrelated to their everyday lives and prevented them from engaging in their everyday activities. Therefore, they were not acting in world-time (i.e. the originary present) to project forward into possibilities in the originary future. Instead, the time spent waiting when the participants attended haemodialysis therapy was characteristic of the empty time of profound boredom, described by Heidegger (1995). Moreover, they had to repeatedly endure the empty time of profound boredom every time they attended haemodialysis therapy.

According to Heidegger, the suspension of originary temporality in profound boredom paradoxically illuminated the threefold structure of originary temporality to Dasein (Hoffman, 2005). When the threefold structure of originary temporality was suspended, it stood still and time appeared to be unreasonably long (Haar, 1999).

Heidegger (1995) claimed that:

In boredom, *Langeweile*, the *while* [Weile] becomes *long* [lang]. Which while? Any short while? No, but rather the while whilst Dasein is as such, the while that measures out that tarrying awhile [*Verweilen*] which is allotted to Dasein as such, i.e., the while whilst it is to be in the midst of these beings... (p152).

Therefore, the while that became long in profound boredom, was the whole while in which Dasein existed. In other words, profound boredom illuminated the time embedded in Dasein's existence, i.e. the time that stretched from birth to death (Hoffman, 2005).

However, by highlighting the "long while" in which Dasein existed, profound boredom ultimately disclosed the shortness of Dasein's existence (Hoffman, 2005). Therefore, the long while that was disclosed through profound boredom actually turned out to be a "short while" - the short while that is allotted to Dasein's finite existence. As Heidegger (1995) conveyed: "It is this whole while-and yet a short while; and so every Dasein in turn is a short while" (p152).

By illuminating the unified structure of originary temporality, profound boredom served to disclose the finitude of Dasein's existence. This confronted Dasein with the [non-chronological] shortness of "its" time (Hoffman, 2005). It was this confrontation with the shortness or finitude of existence, which entranced, or oppressed Dasein in profound boredom. It highlighted to Dasein that its time was running out (Hoffman, 2005).

By disclosing the finite existence of Dasein, profound boredom subsequently gave one the irritating, or distressing feeling of wasting time (Haar, 1999). The feeling of wasting time arose because in boredom, Dasein realised that it was wasting the finite time allotted to its existence. The experience of wasting time also occurred in the

second form of boredom. However, Dasein was not explicitly aware of the existential issue that lay beneath the experience of wasting time, in this second form of boredom.

The distressing experience of wasting time was explicitly contained in the participants' descriptions of waiting, contained in the sub theme *Wasting Time*.⁶² However, it was also inherently contained within the participants' descriptions of *Killing Time*, while they waited for haemodialysis therapy to end. While the participants waited for haemodialysis to end, they did nothing productive. Therefore, the unpleasant experience of wasting time was embedded in their accounts.⁶³

According to Heidegger (1995), the moment when Dasein's finite time was disclosed by profound boredom was the *moment of vision*. It was the decisive moment where Dasein was prompted to make a decision in relation to "its" time, which could turn the disunity of originary temporality into unity.

By confronting Dasein with the finitude of existence, profound boredom prompted it to live in either an authentic or inauthentic mode of existence.⁶⁴ In the inauthentic mode of existence, Dasein absorbed itself in the everyday tasks and activities it performed in world-time to avoid facing the finitude of existence. Conversely, in the authentic mode of existence, Dasein embraced the finitude of its existence, and was subsequently able to project forward into possibilities in life.

It seemed that the profound boredom caused by the participants' experience of waiting, expressed in the theme *Lost Time*, confronted them with the finitude of their existence. This prompted them to live in either an authentic or inauthentic mode of existence. However, the persistent nature of the participants' experience of waiting each time they attended haemodialysis therapy meant they were unable to live in either mode of existence.

⁶² For example, see the accounts of Harrison (p145), Elena (p148), Gloria (p146), Carl (p151).

⁶³ For example, see the accounts of Nancy (p135), Elena (p140), David (p141), Chris (p141).

⁶⁴ See page 125-126 for a detailed account of both modes of existence.

If we recall, the inability to live in either an authentic or inauthentic mode of existence in response to boredom created a disruption in the threefold structure of ordinary temporality. Furthermore, it culminated in the unpleasant and distressing moods we experience on an everyday basis e.g. uneasiness, irritation, frustration, anger, and despair.⁶⁵ These distressing moods were portrayed in the participants' accounts of waiting, contained in the theme *Lost Time*.⁶⁶

For most of the participants, the ongoing experience of waiting each time they attended their treatment meant they continually failed to live in either mode of existence. As a result, the distressing moods, which accompanied their experience of waiting continued to intensify to the level of despair.

Conversely, the follow-up interview illustrated that a small number of participants were able to live in the inauthentic mode of existence in response to profound boredom. For instance, Chris had developed new strategies to pass the time during haemodialysis therapy.⁶⁷ He had commenced a course in computer networks within the last year and spent the time during haemodialysis therapy working, and watching DVDs on his laptop computer. Therefore, he was no longer spending his time during haemodialysis therapy merely waiting for the treatment to end. Instead, Chris was performing activities during the treatment, which were significant in relation to his everyday life. This enabled him to view the time during haemodialysis therapy as being more productive.

Another participant, Carl also expressed his ability to overcome the experience of waiting unnecessarily when he attended haemodialysis therapy.⁶⁸ Carl said that when he initially started haemodialysis therapy, he had wasted a lot of time waiting for a hospital taxi to take him to and from treatment. To avoid waiting unnecessarily before and after haemodialysis therapy, Carl started driving himself to and from the hospital. By organising his own transport, Carl was able to avoid wasting valuable time, waiting needlessly for the hospital taxi. More importantly, he was able to return to work on a full-time basis.

⁶⁵ See page 127-128 for the discussion on the person's inability to live in either mode of existence.

⁶⁶ For example, see the accounts of "killing time" by Nancy (p135), Donna (p139), Alex (p138) and the accounts of "wasting time" by Harrison, (p145), Alex (p146), Elena (p148), David (p149).

⁶⁷ Refer to page 142 for Chris's account.

⁶⁸ Refer to page 151 for Carl's account.

Similarly, Jeff recalled his experience of wasting time, waiting for the hospital taxi to take him to the haemodialysis unit.⁶⁹ By organising his own transport, Jeff was also able to overcome the distressing experience of wasting time.

It is suggested, that the participants' ability to live in the inauthentic mode of existence, enabled them to resolve the disruption in world-time caused by their experience of waiting. It also enabled them to reconnect the threefold structure of ordinary temporality, and alleviate the distressing moods caused by their experience of waiting. Finally, the ability to reconnect the unified structure of ordinary temporality also enabled them to overcome profound boredom.

4.1.4 SUMMARY OF THEME

Within this theme, the participants' experience of waiting when they attended haemodialysis therapy was discussed. The excessive time spent waiting prevented the participants from engaging in their everyday activities, and was interpreted as *Lost Time*. The theme *Lost Time* was constituted by two sub themes: *Killing Time* and *Wasting Time*. The participants described their attempts to kill time, while they waited for haemodialysis therapy to end. They also illustrated their experience of wasting time waiting unnecessarily before and after haemodialysis therapy.

It was proposed that the participants' persistent experience of waiting created a disruption to the characteristic features of world-time and ordinary temporality, advanced by Heidegger (1962). This subsequently culminated in the existential mood of boredom, also depicted by Heidegger (1995). As an existential mood, boredom disclosed the possibility of death to the participants. This prompted them to live in either an authentic or inauthentic mode of existence. However, the relentless nature of the participants' experience of waiting meant they were unable to live in either mode of existence.

⁶⁹ Refer to page 151 for Jeff's account.

The inability to live in either mode of existence created a disruption to the threefold structure of originary temporality. In addition, it culminated in a range of distressing moods, such as uneasiness, irritation, frustration, and anger. For most of the participants, the ongoing experience of waiting meant they were continuously unable to live in either mode of existence. This resulted in the acceleration of the distressing moods, which accompanied their experience of waiting.

In contrast, the follow-up interview showed that a small number of participants were able to live in the inauthentic mode of existence when faced with the possibility of death. These participants were able to reconnect the unified structure of originary temporality and ease their distress. Moreover, they were able to overcome the profound boredom caused by the experience of waiting.

Because of the participants' disheartening experience of waiting each time they attended haemodialysis therapy, several looked forward to receiving a kidney transplant. A successful kidney transplant offered the participants the possibility of freedom from the restrictions and limitations imposed on their lives by haemodialysis therapy. Moreover, it provided them with a potential escape from the distressing experience of waiting when they attended their treatment.

However, in order to receive a kidney transplant, the participants had to be placed on the transplant waiting list until a suitable donor match became available. For most of the participants, this took a substantial amount of time. Hence, the experience of waiting for a kidney transplant was significant for the participants in this study. This experience will now be discussed in the next section.

4.2 THEME 2 - WAITING FOR A KIDNEY TRANSPLANT

The experience of waiting for a kidney transplant was significant for the participants in the study. The theme *Waiting for a Kidney Transplant* consisted of three sub themes:

1. *Living in Hope*
2. *Uncertainty*
3. *Being on Hold*

Many participants described their experience of living in hope, while they waited for a kidney transplant. The hope of a transplant offered the participants the possibility of returning to a normal life in the future. It also enabled them to live through the adversity of life on haemodialysis therapy. The healthcare professionals informed the participants of the average waiting time for a kidney transplant. Based on this information, the participants believed they would receive a transplant within a specific duration of time. Therefore, when they exceeded this duration, they became increasingly uncertain.

The uncertainty of waiting indefinitely for a kidney transplant meant that some participants were unable to contemplate possibilities in the future. Moreover, the lifestyle disruptions caused by haemodialysis therapy prevented them from performing many of the activities they took for granted in the past. Consequently, the participants described their experience of being on hold, while they waited for a kidney transplant.

The follow-up interview showed that a small number of participants were able to overcome the experience of being on hold. The ability to participate in normal, everyday activities was a significant factor in this process. It enabled the participants to get on with their lives, while waiting for a kidney transplant. The three sub themes *Living in Hope*, *Uncertainty*, and *Being on Hold*, will now be discussed with the accompanying narratives of the participants.

4.2.1 SUB THEME 1 - LIVING IN HOPE

Several participants described their experience of living in hope, while they waited for a kidney transplant. The hope of a kidney transplant provided the participants with the possibility of returning to a normal life in the future. In addition, it provided them with the strength to endure the experience of being a renal patient. The information received from healthcare professionals in relation to the average waiting time for a kidney transplant, contributed to the participants experience of living in hope. They assumed they would receive a transplant within a specific length of time.

Embedded in the participants' accounts of living in hope, was their predominant focus on clock and calendar time. It is suggested that the participants concentrated on clock and calendar time in an effort to get through the days, weeks, months, and years until the wait for a transplant was finally over.

For instance, at the time of the first interview with Jeff, he had been on haemodialysis therapy for one year. He said that when he first commenced haemodialysis therapy, his consultant informed him that he would probably receive a kidney transplant within a short duration of time. From this information, Jeff understood haemodialysis to be a temporary problem, which would be alleviated by a kidney transplant. Therefore, Jeff described his experience of living in hope, while he waited for a kidney transplant. Beneath Jeff's account of waiting, was his predominant focus on clock and calendar time.

Jeff stated:

Doctor _____ came down and said that they [medical team] would work me up for a transplant as quick as possible...So I got a line fitted and I was on dialysis...I don't really mind dialysis because I know it's going to be short-term, well I hope it's going to be short term anyway. It takes up a lot of time so it does, there's three days of the week gone, I don't get home now until eleven or half eleven at night...I sort of dealt with it [haemodialysis] pretty quickly, because they're [healthcare team] all so good and Doctor _____ said I would get a transplant quickly, so it all happened so fast. They were taking the blood for the tissue type to get it to [hospital laboratory] straight away, and I just felt that I wouldn't be on dialysis for too long. (13/1)

Like Jeff, another participant Danny also described his experience of living in hope while he waited for a kidney transplant. In the first interview with Danny, he was on haemodialysis for one year and seven months. He described how the relentless regime of haemodialysis therapy made him contemplate skipping the treatment. However, the hope of eventually receiving a kidney transplant enabled Danny to get through life on haemodialysis therapy. Consequently, he used the analogy of the “light at the end of the tunnel” to illustrate his experience of living in hope, while he waited for a transplant.

Seeing other patients being called for a transplant and leave the dialysis unit contributed to Danny’s experience of hope. These patients served to reassure him that one day he would also be called for a transplant.

This was Danny’s account:

*The hope that the phone will ring one day and that I’ll get a transplant, and that life will be completely normal, well almost, then at least I won’t have to come in here three evenings a week...I know I’ll be on medication but at least I’ll be able to come and go and be more normal...it is that [hope of a transplant] that keeps me going...some days I think I can’t be bothered going in for dialysis but then I know it’s a stupid thing to do, but the thought has crossed my mind, but then other days, I think well at least there is a light at the end of the tunnel...even more so now after being here [on dialysis unit] and seeing people going off and getting their transplants...it’s great to see patients who get their kidney and are off dialysis...good for them...one of these days the phone is going to ring [for me] ...it is that bit of hope that keeps you going.
(7/1)*

Other participants used Danny’s analogy of the light at the end of the tunnel to characterise their experience of hope, while they waited for a kidney transplant. This hope enabled the participants to tolerate everyday life on haemodialysis therapy.

For example, in the first interview with Liz, she had been on haemodialysis for two years and nine months. It had taken Liz over a year to get her name on the transplant list, as she had been overweight. According to the Department of Organ Procurement and Transplantation in Ireland, the Body Mass Index (BMI) of the person had to be below 32 before s/he was considered for transplantation. Consequently, Liz was above this BMI figure, and it had taken her a while to lose weight before her name was entered onto the transplant list.

At the time of our first interview, Liz had been on the transplant waiting list for one year and eight months. She described her experience of living in hope, while she waited for a kidney transplant:

Hopefully I'll get a kidney soon and that'll be the end of it [dialysis], you always live in hope...there's light at the end of the tunnel, there's hope there...because coming in here [to dialysis] you meet patients and they get their transplants and it gives you great hope to see someone getting a transplant. (15/1)

I asked Liz what she would like to do if she received a kidney transplant and she replied:

Oh I'd be able to spend more time with my children, and do things...just to have freedom...not to be thinking about coming in here all the time. You go to bed at night and say "oh dialysis tomorrow" and the kids are even beginning to say to me "dialysis tomorrow mam". (15/1)

Liz's account emphasised the loss of freedom she experienced due to the restrictions of haemodialysis therapy. Therefore, by receiving a kidney transplant, she hoped she would be freed from the confines of dialysis therapy and allowed to spend more time with her children. Liz's account signified that she predominantly focused on clock and calendar time, while she waited for a kidney transplant.

Similarly, Alex also confirmed that the hope of a kidney transplant enabled him to remain positive about life on haemodialysis therapy. Before he commenced haemodialysis therapy, Alex used to attend the outpatients department of the hospital for monitoring of his kidney function. While he waited to see his doctors, he had the opportunity to talk to patients who had received kidney transplants, and were living normal lives.

These patients provided Alex with a positive outlook on kidney transplantation, which enabled him to remain upbeat about haemodialysis therapy. His narrative epitomised the belief that haemodialysis was a short-term problem, which would be alleviated by a kidney transplant.

I'd met people who had transplants and I realised it's [dialysis] actually not as bad as I thought it was...I met one guy who had a transplant twenty five years ago and it's still working fine, the average is sixteen years and to hear that, it's not bad...that's the way I looked at it, if someone said you could have twenty five years fairly relatively trouble free, it's not too bad...it's [dialysis] a bit uncomfortable for maybe a year or two but after that, if I look after myself and if luck is on my side it [kidney transplantation] can go well. (3/1)

David's account, like those shared by the other participants, reflected the theme of waiting as living in hope. In the first interview with David, he had been on haemodialysis therapy for one year. When he commenced haemodialysis therapy, the healthcare team informed him that he would be eligible to receive a kidney transplant. Therefore, he was waiting for an appointment for a pre-transplant medical assessment, which would allow him entry to the transplant waiting list. David's account exemplified how the perspective of clock and calendar time was ingrained within his experience of living in hope.

He said:

You're living in hope [of getting a transplant], you just feel like it could be tomorrow, it could be a year from tomorrow, it could be any day...That's the way I think, it [the transplant] will happen but you have to wait. (9/1)

The possibility of eventually receiving a kidney transplant enabled David to maintain a positive outlook on haemodialysis therapy. Indeed, he even described the gratitude he felt toward the haemodialysis machine for allowing him to survive.

It's [dialysis] not bad, I don't feel it's really bad, and aren't we very lucky that we have something that's keeping us alive, if we hadn't dialysis, where would we be, there was a time that there was no dialysis and what did people do...just die, so aren't we lucky. (9/1)

At the time of the first interview with Carl, he had been on haemodialysis therapy for one month. He seemed uncomfortable being attached to the machine and was not very talkative during the interview. However, in the follow-up interview, Carl had been on haemodialysis therapy for one year and one month. He appeared much more settled in the environment of the haemodialysis unit and talked in detail about his experience.

Carl described his experience of living in hope, while he waited for a kidney transplant. He had been aware for two years before he commenced dialysis therapy that his kidney function was deteriorating. Consequently, his name was entered on the transplant waiting list about five months before he began the treatment. He said that he had met and talked with other patients who had successful kidney transplants. This enabled Carl to remain hopeful of eventually returning to a normal life.

I'm still waiting, I'm on it [the transplant list] nearly a year and a half...but it's going grand now, hearing about people getting it [transplant] is encouraging while you're waiting for it...I was talking to a few people that had transplants, I have a neighbour who had a transplant and he was telling me about it ...I see him there and he's working away and flying around the place. I had seen him before he got his kidney and he was in a bad state, he's in his fifties and he was very down and weak, and you see him now and he's working away and driving, it's grand to see that, it gives you a lot of hope that you could be like that as well, he has his life back and all his time to himself again.
(5/2)

In both interviews with Ali, he signified that the hope of receiving a kidney transplant enabled him to tolerate the relentless regime of haemodialysis therapy. Ali was fifty-five years of age and had first commenced haemodialysis therapy when he was twenty-two. He received his first kidney transplant within two years. However, the transplant failed after just six weeks, initiating a return to dialysis therapy. Ali then received another transplant thirteen years later, which functioned for seventeen years.

The following narrative was taken from the follow-up interview with Ali, when he had been on haemodialysis therapy for three years. He was not yet on the transplant waiting list, but was going through the pre-transplant assessment process. Like the other participants, Ali's narrative highlighted his focus on clock and calendar time, while he waited to eventually receive a kidney transplant.

Well they're doing the work up [pre-transplant assessment] at the moment, and actually this day week I'll be having my stress test...and all the other tests are done, so if the stress test was over, please God I should be getting on it [waiting list] then, I should hear from ___ [transplant unit] hopefully within the next month or so...that's providing of course that I'll pass the stress test, but hopefully I will...I'm absolutely delighted...If you're on the list there's hope, there's light at the end of the tunnel. (2/2)

The follow-up interview with some participants illuminated that their experience of living in hope changed to uncertainty overtime. This change in their experience was incorporated in the following sub theme titled *Uncertainty*.

4.2.2 SUB THEME 2 - UNCERTAINTY

Many participants described the experience of uncertainty, while they waited for a kidney transplant. The participants' accounts specifically conveyed how the information they had received from the healthcare team about the average waiting time for a kidney transplant, contributed to their uncertainty. It was normal practice for the healthcare team to inform patients of the average length of time they could expect to wait for a kidney transplant. This information was mostly given at the time of the participants' diagnosis with ESRD, and offered hope at this particularly difficult time.

It is important to point out that the average waiting time for a kidney transplant is merely an estimate, and many patients wait well beyond this time frame. However, it seemed that several of the participants interpreted the average waiting time to mean the "actual" waiting time for a kidney transplant. While this belief allowed the participants to live in hope as they initially waited for a kidney transplant, it did not sustain their hope in the long-term. When the participants either reached or exceeded the "expected" date for a kidney transplant, they became uncertain.

When confronted with uncertainty, the participants became increasingly concerned about their possibilities for the future. Without a definite endpoint to the wait for a kidney transplant, they began to recognise that haemodialysis therapy was not the temporary problem they had initially anticipated. Indeed, beneath the participants' accounts was the dismal possibility that they might never receive a kidney transplant. Thus, the distressing feelings of sadness, disappointment, hopelessness, and despair were threaded throughout their narratives.

Some participants illustrated their experience of uncertainty in the first interview. At the time of the interview, these participants had already reached, or exceeded the average waiting time for a kidney transplant. Conversely, other participants described their

experience of uncertainty in the follow-up interview. Their narratives illuminated how their experience of living hope had changed to uncertainty overtime.

As a result of the uncertainty of waiting indefinitely for a kidney transplant, the participants lost trust in the healthcare team. They began to suspect, that the previous information they had received about the average waiting time was inaccurate.

For instance, in the follow-up interview with Jeff, his previous experience of living in hope, while he waited for a kidney transplant had changed. If we recall, the information Jeff received from his consultant led him to believe that he would receive a kidney transplant within a short duration of time.⁷⁰ However, by the time of the follow-up interview, Jeff had been waiting almost two years for a kidney transplant. Therefore, he was becoming increasingly uncertain about his possibilities in the future.

Jeff's account signified that he had expected to wait between twelve to eighteen months for a kidney transplant. However, since he had exceeded this duration, Jeff's despair was apparent, as he began to wonder if there would ever be an end to haemodialysis therapy.

Jeff recounted:

Well in the beginning, I was told that the average waiting list [for a transplant] was around twelve to eighteen months, so when I started on dialysis I had sort of two years left out in my head for it all to be over...but I'm nearly two years on dialysis now, so you just don't know...it's waiting all the time...I was told that I wouldn't have to wait that long [for a transplant] at all because I was young, and I'm waiting nearly nineteen months now. (13/2)

Because of Jeff's uncertainty, the initial admiration he had towards the healthcare team had been replaced by mistrust and resentment. His account implied that the healthcare team had not addressed his misapprehensions about the waiting process for a kidney transplant. Correspondingly, Danny also illustrated how his experience of living in hope had changed to uncertainty overtime.⁷¹ According to Danny, the healthcare team had informed him that the average waiting time for a kidney transplant was eighteen months to two years. However, at the time of our follow-up interview, Danny had been on the

⁷⁰ See page 173 for Jeff's previous account of living in hope.

⁷¹ See page 174 for Danny's previous account of living in hope.

transplant list for two years. Consequently, the reassurance he initially obtained from seeing other patients receive a kidney transplant, had now turned to disappointment and despair, as he questioned “why not me?”

In particular, Danny’s earlier perspective of a transplant, as the light at the end of the tunnel had been challenged, since the end of the tunnel was no longer in sight. The uncertainty of waiting indefinitely for a kidney transplant meant that his possibilities for the future had diminished. As a result, Danny was faced with the realisation that he might have to tolerate life on haemodialysis therapy for much longer than he had initially suspected.

Danny implied that at the time of his diagnosis with ESRD, the healthcare team informed him of the average waiting time for a kidney transplant. Apart from this superficial information, it seemed he had received no further information and support during the wait. Therefore, his unrealistic beliefs about kidney transplantation were never rectified. Danny said:

I thought...well because you hear the figures eighteen months to two years banded about, that I'd have got a transplant...and then you come in here [to the dialysis unit] and you talk to people and you listen to the patients, and you find out how long they've been on dialysis, and the figures just vary so much, you think, well it could be another couple of years, [it could be] a lot longer than I anticipated...When I first came to the clinic before I started dialysis I'd ask [the healthcare team] what was the average [waiting time for a transplant], and that was the figure I was given then, but that was like three or four years ago...the average wait was eighteen months to two years, but I've heard of people having transplants just after a few months, and then there's people that have been waiting five to six years...It's hard not to think “well why not me?”...I have days when I've had a bad day at work and I don't want to be in dialysis...I get days when just the thought of coming here...I could just turn the car around and drive off home and not bother...and you think well how come some people...I've met them here, I've seen them start dialysis, I've seen them go and have a transplant and they're gone, and I'm still here. “Why am I still here? Why am I here? Sometimes I think maybe I'm going to be waiting a long time, I better just get used to the idea. (7/2)

In the first interview with Liz, she presented her experience of living in hope, while she waited for a kidney transplant.⁷² In particular, seeing other patients being called for a transplant strengthened her experience of hope. By the time of the follow-up interview, Liz had received a kidney transplant one month previously. I asked her what it had been like to wait for a transplant for the past year, and she recalled:

I waited almost three years [for a transplant]. At first, you're so worked up after being told [by the healthcare team] you're on the waiting list, you're thinking "yea, great, great", and then after a few years, you think it's never going to come...and the occasional time you might hear somebody got a transplant you say "will my day ever come?" You just get to a stage where you think it's [the transplant] never going to happen...you go into the dialysis unit and you hear somebody was called [for a transplant] and you'd be delighted for them but still your heart would drop when it wasn't you. (15/2)

Liz's account signified how her hope gradually declined due to the uncertainty of waiting indefinitely for a kidney transplant. As the waiting time increased, it was no longer a source of hope to see other patients being called to receive a kidney transplant. Rather Liz, felt disappointment and despair when she witnessed other patients receive a transplant, while she remained on haemodialysis.

Similarly, the follow-up interview with David also exemplified how the continuous wait for a kidney transplant had turned his hope to uncertainty. In the previous theme, David described how the hope of receiving a kidney transplant enabled him to maintain a positive outlook on haemodialysis therapy.⁷³ However, in the follow-up interview, he said he had been to the transplant unit twice for an assessment. On both occasions, David's BMI was greater than 32, and he failed to gain entry onto the transplant waiting list.⁷⁴

Like the other participants, David believed he would get on the waiting list and receive a kidney transplant within a short duration of time. However, after being on haemodialysis therapy for two years, he had still not achieved this goal. Therefore, his previous experience of living in hope had given way to uncertainty.

⁷² See page 175 for Liz's previous account of living in hope.

⁷³ See page 176 for David's previous account of living in hope.

⁷⁴ The transplant unit stipulates that the person's Body Mass Index (BMI) must be below 32 before transplantation is considered.

When confronted with uncertainty, David had become increasingly concerned about his future possibilities. Without any real chance of a kidney transplant in the near future, he was faced with the stark reality of being “stuck” on haemodialysis for the rest of his life.

David stated:

I've been to _____ [the transplant unit] twice...they [medical team] say I'm over weight...I'm really trying so hard, but it's impossible to get the weight down. I'm down about four kilos, so I'm having another check in _____ [the transplant unit] next month to see if I can get on the list...but he [consultant] probably won't [put me on the list] unless I lose more weight...so maybe I would get on the list but maybe not...the longer it [waiting for a transplant] goes on, the worse you feel about it...at the beginning, you don't realise what's going on, you have no knowledge of what's happening at all...but after being on dialysis for two years you feel you're going to be stuck here and that's it. (9/2)

David's account verified that he was ill informed about the process of kidney transplantation. The healthcare team should have been aware that patients with a BMI above 32 were not considered eligible for transplantation. Therefore, it would seem reasonable to suggest that they would pass this information on to the patients. This would have prevented David from making the disappointing journey twice to the transplant unit, merely to be told he was unsuitable for transplantation. More importantly, it would have allowed him to participate in a weight loss programme to reduce his BMI.

In contrast, David's account emphasised that he did not receive any follow-up information or support, while he waited for a kidney transplant. Indeed, despite being unable to lose weight, he was about to make another fruitless journey to the transplant unit for another assessment.

Some participants described their experience of uncertainty in the first interview. At the time of the interview, these participants had already exceeded the length of time they expected to be waiting for a kidney transplant. For example, in the first interview with Nancy, she discussed her experience of uncertainty when she exceeded the average waiting time for a kidney transplant. When Nancy commenced haemodialysis therapy, the medical team informed her that she would be waiting for “a year and a bit” for a

transplant. Consequently, she interpreted this information to mean that she would definitely receive a kidney transplant within two years.

However, at the time of our first interview, Nancy had already been on haemodialysis therapy for four years. She signified that the uncertainty of waiting indefinitely for a kidney transplant had turned her hope to despair and devastation. As a result of Nancy's experience, she expressed the need for more realistic information from the healthcare team regarding the waiting time for a kidney transplant.

Yes, I'm on the [transplant] list...I've had the check up in ____ [the transplant unit] and I have antibodies, but I'm on the [transplant] list...but the doctors said I'd be waiting for about a year and a bit to get the transplant...then it became two years and a bit, three years and a bit, and now it's four years...people shouldn't listen to this! If there is one thing that needs to be changed and it's that [what the doctor says about transplantation] because you do hang on to it, you think, ok I can do a year or two years on dialysis, but then it's devastating when you pass the two years. (16/1)

Similarly, Chris also emphasised the need for realistic follow-up information in relation to the waiting process for a kidney transplant. He stated that the transplant coordinator had informed him that he would receive a kidney transplant in about a year. However, at the time of our first interview, Chris had already been on the transplant waiting list for over a year.

Chris's account confirmed that he was becoming increasingly uncertain because of exceeding the average waiting time for a kidney transplant. He had begun to question the fairness of the waiting process, and the honesty of the healthcare team.

Well, the thing I don't understand is that the transplant co-ordinator told me it's a years waiting list...and I find out from here [ward] that there's only been like two transplants here in the last year...and I think there is more than fifteen people on the list, so I don't know how it adds up...I'm just wondering, are they telling me the good news [because] they don't want to give me the bad news that it's more than a year...If somebody said to me I would have to wait another year [for a transplant], it would be like a nightmare...I think they [healthcare team] should tell us straight and I hope they are, because if they say a year and it takes three years...there are alternative decisions I could make, maybe not make but explore...I hope to get it within a year, maybe a little over or within a year. (6/1)

Chris's narrative implied that he found the relentless regime of haemodialysis therapy difficult to bear. Therefore, to have to wait another year would be like a "nightmare" for him.

The first interview with John also characterised the uncertainty of exceeding the average waiting time for a kidney transplant. At the time of the interview, John had been on haemodialysis for five years. He had previously been on dialysis in another country but re-located to live in Ireland.

John expressed his disbelief at the lengthy waiting time for a kidney transplant. In particular, he said that if he received a kidney transplant, he would like to return to work. However, his history of chronic renal failure, combined with five years on haemodialysis therapy meant John was increasingly uncertain about the possibility of ever returning to work.

In the UK the waiting list was supposed to be eighteen months to two years on average, and here it's supposed to be a year on average, so it's bad luck to be five years without one [a transplant] ...There was a bloke who went on the list the same day as me in 2001 and he got one a fortnight later...I find it hard to believe its been so long...I'd like to work again if I was well enough [with a transplant] ...I just don't know how far down the slippery slope my heart has gone and my circulation...all them years with damaged kidneys, and then five years on dialysis...I might not be that healthy...I don't know how healthy I'm gonna be if I get one. (14/1)

The uncertainty of waiting relentlessly for a kidney transplant prevented some participants from being able to visualise possibilities in the future. Therefore, they described their experience of being on hold, while they waited for a kidney transplant.

4.2.3 SUB THEME 3 - BEING ON HOLD

As a result of the experience of uncertainty, some participants were unable to contemplate possibilities in the future. Moreover, the limitations and restrictions imposed by haemodialysis therapy prevented them from performing many of the everyday activities they took for granted in the past. Consequently, the participants described their experience of being on hold, while they waited for a kidney transplant.

The participants' accounts implied that the time spent on hold, was a time held back or disconnected from the narrative of their lives. It was almost entirely constituted by the repetitive regime of haemodialysis therapy. Hence, the moods of sadness, disappointment, depression, hopelessness, and despair were palpable throughout their accounts.

The follow-up interview signified that two participants had overcome the experience of being on hold, while waiting for a kidney transplant. The ability to re-engage in everyday activities, such as work was an important part of this process. The participants' accounts of being on hold will now be discussed.

In the first interview with Chris, he described his experience of being on hold, while he waited for a kidney transplant. He said that being able to work was a significant factor in his life. However, since he commenced haemodialysis therapy, he had been unable to work, and was becoming increasingly concerned about his financial situation.

Chris worked as a carpenter before he commenced dialysis therapy, and his job was physically demanding. However, the repetitive nature of the treatment regime, combined with the physiological complications meant he had not been able to return to work. Until Chris was able to return to work, he found it difficult to visualise any possibilities for the future. Therefore, he described his experience of being on hold, while he waited for a kidney transplant, which would allow him to achieve this goal.

My life is on hold...because I worked in construction as a carpenter, I worked in the commercial end of carpentry and some jobs can be physical, your life is on hold...but right now that the fistula has kind of straightened out and I'm on the [transplant] list, I'm kind of looking to get back to work a few days a week...Before that up to two weeks ago, I couldn't because I was in the hospital for infections and I don't know what employer will employ you if you're taking every second day off or a few days a week off...but I'm looking to work three days a week now but that's about it...I see a future if I get a transplant, it's mainly about work...how are you going to survive and pay your bills...you have to come in here three times a week for four and a half hours...it's continuous, until you get a transplant. (6/1)

Chris's account illustrated how his experience of being on hold culminated in feelings of hopelessness and despair.

Like Chris, the first interview with Nancy also characterised her experience of being on hold, while she waited for a kidney transplant. Nancy's anecdote conveyed that while she waited for a kidney transplant, her life was engulfed by the repetitive regime of haemodialysis therapy. She emphasised how the restrictions and limitations imposed on her life by haemodialysis therapy prevented her from participating in normal everyday activities such as working, going on holiday, and socialising.

This was Nancy's account:

You're always constantly aware of dialysis...you'd love to just pick up a brochure and go on holiday but you can't because it's constantly there...and you say to yourself "well when I get the transplant, I'll be back to normal", you look at life as if it's on hold until you get a transplant...I mean I find the diet and the fluids ok but you're very aware of it...I was at the wedding there last week and I wanted to relax and have a few drinks but in the back of your head you think it will overload you...to me your life is on hold because you're not doing what you want to do...I know I have to follow these rules but it gets in the way of work, it gets in the way of a normal routine...it's like I'm bonded to it [dialysis]...I'm always walking around with it, and when you do get the transplant it's like the shackles are gone. (16/1)

Nancy's narrative illustrated that the time spent on hold waiting for a transplant, was incompatible with the narrative of her life. Therefore, she felt like a "different person" while she was forced to continuously endure the repetitive regime of haemodialysis therapy. Embedded in Nancy's account was the hopelessness and despair caused by the experience of being on hold. She yearned to return to the normal life she enjoyed prior

to haemodialysis therapy. However, Nancy was unable to contemplate possibilities for the future, until she received a kidney transplant, which would allow the “shackles” of dialysis to be removed.

For John, the inability to return to work was the predominant factor contributing to his experience of being on hold, while he waited for a kidney transplant.

He said:

Well I do think my life is on hold because I worked until just before I started dialysis, and there's days when I feel I could work now, and there's days when I know that I couldn't...so if I got a job, I know I wouldn't be able to keep it and I'd be off all the time...If I was in work, my performance would be pretty poor, like falling asleep at your desk and that kind of thing, that's how I was before I gave up work. (14/1)

In the follow-up interview with David, I asked him if he felt on hold, while he waited for a kidney transplant. He replied:

I sure do feel on hold...There's times when you get down to the bottom of the dumps...you're waiting and sometimes you think it's [the transplant] never going to happen...because I heard on the radio a few days ago that there are 550 people on the [transplant waiting] list and there was only 120 transplants this year...you just get really, really pissed off with it [waiting], and you feel it's never going to happen...that's the way I feel at the moment really...You get a bit depressed at times, you feel it's never going to happen, and you get to a stage and you say, “why am I trying so hard to get on this thing [transplant list]?” There's no hope for me getting on it [the transplant list]...there's so many people on there at the moment, and you just feel “Is my day ever going to come?” (9/2)

David's account highlighted the sadness, depression, and despair caused by the experience of being on hold, while he waited for a kidney transplant. The absence of a definite endpoint to the wait meant that David was unable to contemplate any possibilities for the future.

Like the other participants, David assumed he would receive a kidney transplant within a specific length of time. However, by the time of our follow-up interview, he had well exceeded this duration, and was still waiting to get his name on the transplant waiting list. Consequently, he felt depressed because he realised that his wait for a kidney

transplant was going to be a lot longer than he had initially predicted. Indeed, the information David had recently heard on the radio, merely confirmed this bleak reality.

The fear of missing out on the opportunity to receive a kidney transplant played a part in some participants' experience of being on hold. For instance, in the follow-up interview with Jeff, he highlighted how his life centred on the "waiting game" for a kidney transplant. Therefore, he signified that he was on hold until he eventually received the call to receive a kidney transplant. Embedded in Jeff's account of being on hold was the fear of missing out on the call for a kidney transplant.

You're on hold so you are...it's just a big waiting game now...waiting for that call [for a transplant]...you never leave the phone, you have the phone with you 24/7...I thought that I would have got the transplant by now, but now I feel that it should definitely come in the next six months but you're just hoping that it will...but you don't know like...it's still on hold. (13/2)

As Jeff's narrative progressed, he described how the restrictive nature of the haemodialysis treatment regime also contributed to his experience of being on hold. He implied that his life was almost entirely constituted by the repetitive treatment regime, while he waited for a kidney transplant.

Every Tuesday, Thursday, Sunday for the past twenty three months...you're just planning to go to dialysis...you're watching everything you eat, everything you drink...after getting the transplant, I think you'd get your life back anyway...you feel as if your life is on hold...it wouldn't be on hold then, you could go out and you could have a drink, you could eat whatever you wanted, you'd go back to a normal life then again. (13/2)

Similarly, Danny also signified that he had decided to put his life on hold, while he waited for a kidney transplant. Before Danny commenced haemodialysis therapy, he used to work as a lorry driver. However, at the time of our first interview, he indicated that he rarely worked, because he was afraid of missing out on the chance to receive a kidney transplant.

The fear of missing out on a transplant also prevented Danny from visiting his family in the UK. Therefore, he described his experience of waiting for a transplant, as being held back in a time, which revolved around the repetitive regime of dialysis therapy.

My life is on hold...very, very much so...I can't plan anything, can't go anywhere...I'm waiting for the phone to ring...when are you going to get that call for a transplant...The odd weekend away is as much as you can manage...then you can't go far because [you might be called for a transplant]...I have family over in the UK and I would like to see them for a weekend, but it's completely out of the question...you can't plan...a call is going to come out of the blue and that can impact on your work because I might get a days work but they [employers] will say "you've got to go to the other side of the country"...what happens if the phone rings...I could earn a bit more money but there's always that chance [I might be called for a transplant]...everything [emphasis] revolves around dialysis. (7/1)

As Danny's narrative continued, he emphasised the financial implications of not working. For instance, there were times when he struggled to pay bills and buy food. While Danny remained on hold, waiting for a kidney transplant, he was confined to the house with "nothing to look forward to". Therefore, the distressing moods of sadness, hopelessness, and despair were implicitly contained within his account.

When your stuck in the house and can't work...I'd be staring at the wall...that's when I get the bad days...if I have nothing to look forward to in the week but dialysis...Sometimes I wonder how I manage, because by the time I've paid rent, gas, electric, there's very little [money] left...I thank God for a renal diet sometimes because you get a good bit of rice and pasta for a few euros...If was eating what I used to eat I couldn't afford it. (7/1)

A year later in the follow-up interview with Danny, he had begun to realise that he could potentially have to wait a long time for a kidney transplant. This realisation encouraged Danny to return to work, and get on with his life, while he remained on haemodialysis therapy.

In particular, the financial implications of being unemployed had been the catalyst for Danny's decision to return to work. He found it extremely difficult to manage financially on the benefits he received from social support. Consequently, he felt he had no choice except to seek employment, in an effort to earn some money.

By recommencing work, Danny had been able to overcome the experience of being on hold, while he waited for a kidney transplant. As a result, he was able to look forward to possibilities in the future. Indeed, he signified that he was looking forward to a trip to

the UK to go shopping with his family. According to Danny, this would not have been possible the last time we spoke.

Danny stated:

When I first got on the [transplant] list, I thought any day the phone will ring, and the guys I worked for were asking, "Can you go here? Can you go there?" and I was saying, "no, I can't, I need to be near home, if the phone rings, I've got to go". But as time has gone on, I think this isn't going to happen realistically now...I've got to accept the fact and I can't put my whole life totally on hold waiting for that phone call...that's why I've gradually got back into more work, driving longer distance, doing longer hours, because I need the money...What they pay you on social [support] wouldn't buy peanuts, so it's a case of having to...I've had to out of necessity take on more work, I've had to sort of say "well I can't just put everything on the back burner and sit by the fire waiting for that day to come" because it could be two more years even, and I've bills to pay and rent to pay like everybody else...the money has to come from somewhere, so that's where I'm at now...[before] I would be sitting at home earning nothing...That fear that you wouldn't be ready to go [if you were called for a transplant] and that your chance would be gone...It was dreadful because I've never been a person to sit around doing nothing if there's work to be done, and then to be suddenly sat in front of the TV, it's something I've never, ever done or got used to doing...But it was literally a case of getting used to the fact that this [transplant] probably isn't going to happen tomorrow, or the next day, or six months, or twelve months, or eighteen months...I've got to get used of the idea that I've got to get back into my life, get on with life and get on with earning, and do as many normal things as I can...I try as much as I can, although it's still a routine...I plan ahead now, like I've planned Christmas, I'm going to ___[UK] shopping, I'm going to take off at the weekend and just go shopping, I've planned and organised Christmas, so I'm pretty much trying to get on with it [life] as best I can, I couldn't have done that the last time I spoke to you. (7/2)

The follow-up interview with Chris also demonstrated that he had been able to overcome the experience of being on hold, while he waited for a kidney transplant. If we recall, Chris's inability to return to work was the main factor contributing to his experience of being on hold. He insisted that he was unable to visualise a future until he received a transplant, which would allow him to return to work.

However, in the follow-up interview, Chris had accepted that working, as a carpenter was potentially too strenuous, either on haemodialysis or with a kidney transplant. During the past year, he had undertaken a course in computer networks, in an effort to get a more suitable job. By actively pursuing a change in career, Chris had been taking

active steps to return to employment. Consequently, his narrative indicated that his life was “not so much on hold” as the last time we spoke.

Well it's [life] not so much on hold...I can do things...I'm waiting for a transplant but I'm thinking if I get a transplant, I might not be able to do construction, so I'm looking down the road...maybe it's [construction] not the best thing to be doing, health wise...so I know something about computers and I decided to do some exams and try and get a job at that...It's interesting, I did it before years ago, I did computers for two years, I like working with them...I did a FAS course for eight months on computer networks, so that got me into it a bit more...so now I just want to do some more exams...If I'm looking for a job I guess the more certificates you have, the better. (6/2)

The accounts of Danny and Chris suggested that their ability to re-engage in normal, everyday activities, such as work allowed them to overcome the experience of being on hold, while they waited for a transplant. Moreover, it enabled them to get on with their lives while they remained on haemodialysis therapy.

4.2.4 DISCUSSION OF THE THEME

It is proposed that time played a central role in the participants' experience of waiting for a kidney transplant.⁷⁵ In particular, Heidegger's phenomenological notion of time seemed to capture the perspective of time characterised within the participants' accounts. Therefore, the three modes of time described by Heidegger (1962) provided an overarching framework for the discussion of the participants' experience of waiting for a kidney transplant.

Several participants described their experience of living in hope, while they waited for a kidney transplant.⁷⁶ The information received from the healthcare team in relation to the average waiting time for a kidney transplant, contributed to their experience of living in hope. It led the participants to assume they would receive a kidney transplant within a definite duration of time. It is suggested that this assumption encouraged the participants to focus on clock time up until they reached or exceeded the average

⁷⁵ This theme will also be discussed in relation to a broader body of literature (specifically the work of Janice Morse) in Chapter 5: *Discussion of the Findings*.

⁷⁶ For examples of the participants' experience of living in hope, see the accounts of Jeff (p173), Danny (p174) & Liz (p175).

waiting time for a kidney transplant. If we recall, the participants' accounts of living in hope, while they waited for a kidney transplant, illustrated their predominant focus on clock and calendar time.⁷⁷ By focusing on clock and calendar time, the participants were able to get through the days, weeks, months, and years until the wait for a transplant was finally over.

As previously mentioned, Heidegger (1962) used the term ordinary time to describe the infinite, irreversible sequence of "nows" that we refer to as clock time.⁷⁸ However, he insisted that the concept of time was much more extensive than this theoretical perspective. According to Heidegger (1962), we did not normally understand ordinary or clock time as an abstract entity that consisted of an infinite, irreversible sequence of "nows". On the contrary, he claimed that we understood clock time in relation to the everyday activities we performed in the world (Blattner, 1999).

World-time was described by Heidegger (1962), as the time that contained the activities, which we carried out in our everyday involvement in the world. When we referred to ordinary or clock time, it was usually to structure and coordinate our activities in world-time. Therefore, Heidegger (1962) contended that ordinary time originated out of world time, while world-time subsequently originated out of originary temporality.

Through world-time, originary temporality provided the basis and context of ordinary time. This meant originary temporality provided the contextual, existential background of ordinary time. However, Heidegger (1962) insisted that if we merely focused on the endless, empty sequence of "nows", this contextual background of ordinary time remained hidden (Blattner, 1999). By observing time from this abstract perspective, the features of world-time and originary temporality, which provided the background to ordinary time were essentially covered up or concealed.

The participants in the study presumed they would receive a kidney transplant within a specific length of time. Therefore, they concentrated on clock time until they reached or exceeded the endpoint of this duration. However, it is suggested that by specifically

⁷⁷ For example, see the accounts of Danny (p174), Liz (p175), Alex (p175), and Carl (p177).

⁷⁸ See page 102 for the previous discussion on ordinary or clock time.

focusing on clock time, the other modes of time, which formed the basis of the participants' experience of waiting, remained concealed or covered over.

When the participants went beyond the "expected" waiting time for a kidney transplant, they experienced uncertainty.⁷⁹ At this point, their perspective of time changed. The participants were no longer focusing on merely getting through the empty "nows" of ordinary time, while they waited for a transplant. They began to realise that haemodialysis was not the short-term problem they had initially anticipated. Instead, their descriptions of uncertainty characterised the grim realisation that they could potentially be on dialysis for the rest of their lives. In the absence of a definite endpoint to their wait for a kidney transplant, the participants grew increasingly concerned about their possibilities for the future.⁸⁰

Heidegger (1962) claimed that as a result of originary temporality, the person was always projecting into possibilities in the future.⁸¹ Indeed, the originary future provided the projection for the unified whole of originary temporality. It was for this reason, that the originary future had priority over the originary past and present. It is proposed, that when the participants became uncertain about their future possibilities in life, the threefold structure of originary temporality was illuminated. These features of the participants' experience of uncertainty corresponded to Heidegger's (1962) description of anxiety (*angst*).

According to Heidegger (1962) anxiety, like boredom was a fundamental existential mood.⁸² Anxiety disclosed the three elements of the "care-structure" of Dasein's being, grounded in the corresponding three ecstases of originary temporality (Hoffman, 2005). If we recall, Heidegger (1962) stated that the care-structure of Dasein's being consisted of three elements: existence, facticity, and falling. Each one of the elements was entrenched within an ecstases of originary temporality (Blattner, 2005). This meant that

⁷⁹ For examples of the participants' experience of uncertainty, see the accounts of Danny (p180), Liz (p181), Nancy (p183) & Chris (p183).

⁸⁰ For example, see the accounts of Jeff (p179), Danny (p180), Liz (p181), John (p184).

⁸¹ See page 94 for the previous discussion on the originary future.

⁸² See page 125 for the previous discussion on Heidegger's notion of anxiety and boredom.

existence, facticity, and falling were embedded in the future, past, and present respectively.⁸³

Anxiety illuminated the unified structure of originary temporality, which formed the basis of the care-structure of Dasein's being (Heidegger, 1962). By illuminating the ecstatic structure of originary temporality, anxiety highlighted that death was one possibility of Dasein's existence (Hoffman, 2005). As previously mentioned, the projection of the originary future provided the projection for the entire ecstatic structure of originary temporality. However, it was also because of the projection of the originary future, that death was one possibility of Dasein's existence (Mulhall, 2005).

As a result of our finite existence, Heidegger (1962) declared that we were dying throughout our life. He emphasised this point when he said, "factically, Dasein is dying as long as it exists" (p295). By illuminating the threefold structure of originary temporality, anxiety (angst) disclosed Dasein's finite time. Thus, like boredom, anxiety was a fundamental existential mood because it highlighted the possibility of death to Dasein. According to Heidegger (1962), when confronted with the possibility of death, the person was prompted to live in either an authentic or inauthentic mode of existence.⁸⁴

It is proposed, that Heidegger's (1962) depiction of anxiety epitomised the participants' experience of uncertainty, while they waited for a kidney transplant. By illuminating the threefold structure of originary temporality, it seemed that the experience of uncertainty illuminated the possibility of death to the participants.

From Heidegger's (1962) perspective, we cover up or evade the certainty of death by absorbing ourselves in everydayness (*falling*).⁸⁵ However, the experience of waiting indefinitely for a kidney transplant created uncertainty in the participants' everyday

⁸³ See page 93 for a more-in-depth discussion on the care structure of Dasein's being in relation to originary temporality.

⁸⁴ In the authentic mode of existence, I am aware of the finitude of my existence, but still project forward into possibilities in the originary future. In the inauthentic mode of existence, I do not acknowledge my finite nature. Instead, I allow myself to be absorbed in the everyday tasks and activities, which occur in world-time to avoid this realisation. The threefold structure of originary temporality remains unified in both modes of existence. See pages 125-126 for in-depth discussion on the two modes of existence.

⁸⁵ See pages 97 for the previous discussion on falling/everydayness.

lives, thus highlighting the certainty of death. Therefore, the experience of uncertainty paradoxically disclosed the certainty of death to the participants.

In this way, the participants' experience of uncertainty depicted Heidegger's (1962) notion of anxiety i.e. it disclosed the finitude of their existence. As a result, the participants were prompted to live in either an authentic or inauthentic mode of existence. However, the uncertainty of waiting on a long-term basis for a kidney transplant meant that some participants could not live in either mode of existence. As previously mentioned, the inability of the person to live in either mode of existence in response to anxiety triggered the unpleasant and distressing moods we experienced in everyday life. Furthermore, it created a disruption to the threefold structure of originary temporality.⁸⁶

It is suggested that the distressing moods of sadness, disappointment, hopelessness, and despair, which were threaded throughout the participants' accounts of uncertainty, indicated that they were unable to live in either mode of existence.⁸⁷ Moreover, the participants' descriptions of being on hold, while they waited for a transplant seemed to characterise a disruption in the unified structure of originary temporality. The uncertainty of waiting indefinitely for a kidney transplant meant the participants were unable to contemplate possibilities for their future. In addition, the lifestyle disruptions imposed by the treatment regime of dialysis therapy prevented them from engaging in many of the everyday activities they took for granted in the past. Consequently, they described their experience of being on hold, while they waited for a kidney transplant.⁸⁸

The participants' experience of being on hold signified that they were unable to engage in either mode of existence when faced with the reality of death. The uncertainty associated with the persistent wait for a kidney transplant suspended their ability to project forward into possibilities in the originary future. Thus, they were unable to live in the authentic mode of existence. Furthermore, the restrictions of the haemodialysis

⁸⁶ See page 127-128 for the previous discussion on the person's inability to live in either mode of existence in response to anxiety and boredom.

⁸⁷ For example, see the accounts of Danny (p180), Liz (p181), David (p182), Nancy (p183).

⁸⁸ For examples of the participants' experience of being on hold, see the accounts of Chris (p185), Danny (p189), Nancy (p186), David (p187).

treatment regime inhibited their ability to absorb themselves in the everydayness of an inauthentic mode of existence.

It is proposed, that the participants' inability to live in either an authentic or inauthentic mode of existence may have created a disruption to the threefold structure of originary temporality. This disruption was illustrated in the participants' experience of being on hold, while they waited for a kidney transplant. For instance, the participants' inability to project forward into possibilities in life implied that the originary future had lost its projective characteristics. If we recall, the three ecstases of originary temporality formed a unified structure with a projective character based on the originary future.⁸⁹ Without the projection of the originary future, the ecstatic unity of originary temporality was disconnected.

Furthermore, it seemed that the participants' experience of being on hold might have also created a disruption to world-time. To re-iterate, world-time referred to Dasein's qualitative experience of time in its everyday involvements in the world.⁹⁰ It was the time that contained the everyday activities performed by Dasein. It is suggested that the participants' inability to engage in their everyday lives and activities, while on hold waiting for a transplant, may have created a disruption to world-time.

Remember world-time constituted the present ecstases of originary temporality. The structure of world-time was embedded in the unified structure of originary temporality. World-time provided the action for the originary present, which enabled the person to project forward into possibilities in the originary future. Based on this perspective, a disruption to world-time would subsequently culminate in a disruption to originary temporality. Therefore, it is proposed that by creating a disruption to world-time, the participants' experience of being on hold, while they waited for a transplant also created a disruption to originary temporality. The disruption in world-time and originary temporality was characteristic of the description of boredom, advanced by Heidegger (1995).

⁸⁹ See page 94 for the previous discussion on the originary future.

⁹⁰ See page 97 for the previous discussion on world-time.

If we recall, Heidegger's (1995) description of boredom was discussed in the previous theme.⁹¹ Heidegger presented boredom as a fundamental existential mood, which disclosed the finitude of our existence. He identified three forms of boredom, which ranged from the most superficial to the most profound. The three forms of boredom were discussed in detail in relation to the previous theme *Lost Time*.⁹²

To re-iterate, the third form of boredom was the most profound, because it illuminated Dasein's finite existence. From Heidegger's (1995) perspective, we all had an unpleasant awareness of the experience of profound boredom within ourselves. It was this awareness, which alerted us to escape from the first and second forms of boredom. Therefore, the third form of boredom was the origin of the other two forms of boredom. The awareness of our finite existence was retained in both the first and second forms of boredom. However, it was more intense in the second form of boredom than the first. For this reason, the second form of boredom was described as being more profound than the first.

By fleeing from the first and second forms of boredom, we avoided oscillating into the third and most profound form of boredom (Heidegger, 1995). However, if we were unable to escape from these forms of boredom, we progressed into the third and most profound form of boredom, described by Heidegger (1995). The third form of boredom confronted us with the stark realisation of our finite existence.

It is proposed, that the participants' experience of relentlessly waiting for a kidney transplant made it difficult for them to flee or escape from the first and second forms of boredom. Hence, they may have been drawn into the third and most profound form of boredom, described by Heidegger (1995). In the account that follows, the three forms of boredom will be discussed in relation to the theme *Waiting for a Kidney Transplant*.

⁹¹ See page 158 for the previous discussion on Heidegger's notion of boredom.

⁹² See page 158 for the previous discussion on the three forms of boredom by Heidegger.

4.2.4.1 *The First Form of Boredom*

According to Heidegger (1995) the first form of boredom occurred when we were forced to wait in a particular situation. The participants in my study had no choice except to wait for a suitable donor to become available, if they wanted to receive a kidney transplant. For many, this took a substantial amount of time.

In the first form of boredom, the time became long and drawn out (Heidegger, 1995). Therefore, the person tried to pass the time in an effort to get rid of the boredom. However, if the person was unable to pass the time, s/he watched the clock (Heidegger, 1995). Concentrating on clock time, or watching the clock was a feature of the first form of boredom. It signified that the person's efforts to pass the time were not successful. When the person watched the clock or focused on clock time, s/he was simply trying to gauge how much time remained before the wait was finally over (Heidegger, 1995).

The predominant focus on clock and calendar time was depicted in the participants' accounts of waiting, described in the sub theme *Living In Hope*.⁹³ The participants' accounts showed that by focusing on clock and calendar time, they were able to get through the duration of time until the wait was finally over. These features of the participants' accounts corresponded to the first form of boredom, described by Heidegger (1995).

According to Heidegger (1995), the first form of boredom occurred when we exceeded the appropriate time for a particular thing. As previously mentioned, the significance of world-time ensured that everything we did in world-time lasted for a particular duration.⁹⁴ However, if we went beyond the time that was appropriate for a specific event, we experienced the first form of boredom.

The participants' accounts signified that they expected to receive a kidney transplant within a particular time span. Therefore, they did not intend to remain on haemodialysis therapy on a long-term basis. Indeed, many of their accounts illustrated that they

⁹³ For example, see the accounts of Liz (p175), Alex (p175), David (p176), Ali (p177).

⁹⁴ See page 100 for the previous discussion on the significance of world-time

understood haemodialysis therapy to be a short-term problem. However, the participants' narratives, portrayed in the sub-theme *Uncertainty*, emphasised the distress they experienced when they exceeded the duration they had intended to wait for a kidney transplant.⁹⁵ By exceeding the “appropriate” waiting time for a kidney transplant, it is proposed that the participants may have experienced the first form of boredom, addressed by Heidegger (1995).

According to Heidegger, the first form of boredom was transient (Aho, 2007). As soon as I escaped from whatever was boring me, I subsequently drove away the boredom. It appeared that the participants' experience of waiting indefinitely for a kidney transplant prevented them from fleeing the first form of boredom. As a result, they may have advanced into the second and more profound form of boredom, described by Heidegger (1995).

4.2.4.2 The Second Form of Boredom

If we recall, the second form of boredom was more profound than the first form, because it seemed to come from something indeterminate and unfamiliar (Heidegger, 1995). According to Heidegger (1995), the indeterminate and unfamiliar thing that caused the second form of boredom was the standing of world-time.⁹⁶

In the discussion of the previous theme, Heidegger's example of attending an evening invitation was used to demonstrate how world-time came to a stand in the second form of boredom. Heidegger (1995) said that when we decided to attend an evening invitation, the activities we normally performed in world-time were brought to a stand. Consequently, the irreversible flow of world-time also came to a stand for the duration of the evening. The standing of world-time was the unfamiliar and indeterminate “something” that bored us in the second form of boredom.

The second form of boredom, described by Heidegger (1995) seemed to epitomise the participants' experience of being on hold, while waiting for a kidney transplant. For instance, the participants described the experience of being on hold, as being unable to

⁹⁵ For example, see the accounts of Jeff (p179), Danny (p180), Nancy (p183) & Chris (183).

⁹⁶ See page 158 for the previous account of boredom.

engage fully in their everyday activities. Indeed, for Chris, Danny, and John, the inability to participate in work seemed to be the primary reason for their experience of being on hold.⁹⁷ It is proposed, that the participants' inability to engage in their everyday activities may have caused world-time to come to a stand. As a result, their experience of being on hold was characteristic of the second form of boredom, described by Heidegger (1995).

Heidegger (1995) used the example of the evening invitation to signify that the second form of boredom was usually transient. It only lasted for the duration of the evening. When the evening was over, we re-engaged in our everyday activities and escaped this level of boredom.

Conversely, the participants' accounts suggested that the experience of waiting for a kidney transplant was not transient. The absence of a definite endpoint to the wait for a kidney transplant meant they had to tolerate the experience of waiting on a continuous and long-term basis. This meant the patients were unable to flee from the standing of world-time, which accompanied the second form of boredom. The participants' inability to flee the second form of boredom, suggested that they might have progressed into the third and most profound form of boredom, described by Heidegger (1995).

4.2.4.3 The Third Form of Boredom

As previously mentioned, the third form of boredom was the most profound type of boredom.⁹⁸ In contrast to the second form of boredom, it was the threefold structure of originary temporality, which was suspended or stopped in the third form of boredom (Haar, 1999). Therefore, Dasein was held in limbo by the suspension of originary temporality. According to Heidegger, when we were held in limbo by the suspension of originary temporality, we were held back from our own possibilities in life, held back from our past and future, and held back from world-time (Haar, 1999). The experience of being held in limbo, by the suspension of originary temporality was expressed in the participants' descriptions of being on hold, while they waited for a kidney transplant.

⁹⁷ See the accounts of Chris (p185), Danny (p189), and John (p187).

⁹⁸ See page 158 for the previous discussion on boredom.

For instance, the absence of a specific end to the wait for a kidney transplant meant the participants were unable to contemplate possibilities in life.⁹⁹ When the participants were held back from their possibilities in life, the originary future lost its projective character. Without the projective function of the future, it is suggested that the threefold structure of originary temporality disintegrated, and the participants were held back from their originary past and future.

In addition, the participants' descriptions of being on hold also signified that they were unable to participate fully in their everyday activities.¹⁰⁰ This suggested that they were held back from world-time. As a result of being held back from world-time, the participants were no longer acting in world-time (originary present), based on their attunements from the past, to project forward into possibilities in the originary future. Therefore, this contributed to the disintegration of the unified structure of originary temporality.

These features of the participants' experience of being on hold conveyed that they were held in limbo by the suspension of originary temporality. As a result, they were compelled to endure the empty time of profound boredom. From Heidegger's (1962) perspective, the person usually acted in the originary present (i.e. world-time) based on his/her affectedness and attunements from the past to project forward into possibilities in the originary future.¹⁰¹ However, when the person was held in limbo by the suspension of originary temporality, the originary present was characterised by inaction. This empty present was the empty time of profound boredom. It culminated in nothing but a repetition of the same present (Haar, 1999). Some participants' descriptions of being on hold confirmed that the time spent on hold, was almost entirely constituted by the repetitive regime of haemodialysis therapy.¹⁰² This feature of the participants' accounts appeared to symbolise the empty time of profound boredom.

Heidegger (1995) indicated that the suspension of originary temporality in profound boredom illuminated the threefold structure of originary temporality to the person. By illuminating the unified structure of originary temporality, profound boredom disclosed

⁹⁹ For example, see the accounts of Chris (p185), Nancy (p186), Jeff (p188), David (p187).

¹⁰⁰ For example, see the accounts of Nancy (p186), John (p187), Jeff (p188), Danny (p189).

¹⁰¹ See page 96 for the previous discussion on the originary present.

¹⁰² For example, see the accounts of Chris (p185), Nancy (p186), Jeff (p188), Danny (p189).

the finitude of the person's existence.¹⁰³ It was this awareness, which oppressed the person in profound boredom. By highlighting the finitude of existence, profound boredom prompted the person to live in either an authentic or inauthentic mode of existence.¹⁰⁴

The participants' descriptions of being on hold signified that they were unable to live in either mode of existence in response to boredom. Moreover, the relentless nature of the wait meant that the participants failed to live in either mode of existence on a long-term basis. To re-iterate, the inability of the person to live in either mode of existence when faced with the possibility of death culminated in the unpleasant and distressing moods we experienced on an everyday basis. In addition, it disrupted the threefold structure of originary temporality.¹⁰⁵

The participants' accounts of being on hold, while they waited for a kidney transplant contained a range of unpleasant and distressing moods.¹⁰⁶ Moreover, the continuous failure of the participants to live in either mode of existence caused these moods to intensify to the level of sheer hopelessness and despair. The participants' inability to live in either mode of existence also prevented them from reconnecting the threefold structure of originary temporality. As a result, they were unable to overcome both the profound boredom and the experience of being on hold, while they waited for a kidney transplant.

In contrast, the follow-up interviews demonstrated that Chris and Danny had been able to overcome the experience of being on hold, while waiting for a kidney transplant.¹⁰⁷ By re-engaging in work on an everyday basis, these participants were able to overcome the experience of being on hold. The participants' efforts to absorb themselves in everyday activities illustrated that they had been able to live in the inauthentic mode of

¹⁰³ See page 125 for the in-depth discussion on how profound boredom discloses the finitude of our existence.

¹⁰⁴ In the authentic mode of existence, I am aware of the finitude of my existence, but still project forward into possibilities in the originary future. In the inauthentic mode of existence, I do not acknowledge my finite nature. Instead, I allow myself to be absorbed in the everyday tasks and activities, which occur in world-time to avoid this realisation. The threefold structure of originary temporality remains unified in both modes of existence. See pages 125-126 for in-depth discussion on the two modes of existence.

¹⁰⁵ See pages 127-128 for the previous discussion on the person's inability to live in either mode of existence.

¹⁰⁶ For example, see the account of Chris (p185), Nancy (p186), David (p187), Danny (p189).

¹⁰⁷ See page 190 for Danny's account, and page 191 for Chris's account.

existence. It is proposed, that by absorbing themselves in the inauthentic mode of existence, these participants were able to reconnect the threefold structure of originary temporality. This subsequently enabled them to overcome the profound boredom and the experience of being on hold, while they waited for a kidney transplant.

4.2.5 SUMMARY OF THEME

The theme *Waiting for a Kidney Transplant* consisted of three sub-themes: *Living in Hope*, *Uncertainty*, and *Being on Hold*. The participants described their experience of living in hope, while they waited for a kidney transplant. The hope of receiving a transplant offered the participants the possibility of a normal life in the future. However, as the time spent waiting continued indefinitely, they became uncertain.

The uncertainty of waiting persistently for a kidney transplant meant the participants were unable to contemplate possibilities for their future. Moreover, the lifestyle disruptions caused by the treatment regime of haemodialysis therapy prevented them from taking part in their everyday activities. Therefore, they conveyed their experience of being on hold, while they waited for a kidney transplant. Because of the ongoing nature of the wait, most participants were unable to overcome the experience of being on hold. Thus, they experienced unpleasant moods, such as sadness, depression, hopelessness, and despair. Conversely, the follow-up interview highlighted that a small number of participants had been able to overcome the experience of being on hold, and get on with life while they waited for a kidney transplant.

It was suggested that the participants' experience of waiting indefinitely for a kidney transplant culminated in the existential moods of anxiety and boredom, advanced by Heidegger (1962, 1995). As existential moods, anxiety and boredom highlighted the threefold structure of originary temporality to the participants. This disclosed death as a possibility of their existence. When confronted with the possibility of death, the participants were prompted to live in either an authentic or inauthentic mode of

existence.¹⁰⁸ However, the relentless experience of waiting for a kidney transplant meant they were unable to live in either mode of existence.

The participants' inability to live in either mode of existence created a disruption in the unified structure of originary temporality. This disruption was illustrated in the sub theme *Being on Hold*. The failure of the participants to live in either mode of existence also culminated in the distressing moods, contained in the sub themes *Uncertainty* and *Being on Hold*.

Alternatively, the follow-up interview confirmed that a small number of participants were able to absorb themselves in the inauthentic mode of existence when faced with the possibility of death. These participants were able to reconnect the three ecstases of originary temporality and alleviate the distress caused by their experience of waiting. For the participants who could not achieve this aspiration, the unpleasant moods continued to intensify to the point of sheer hopelessness and despair. They were unable to reconnect the threefold structure of originary temporality. Consequently, they were also unable to overcome the profound boredom and experience of being on hold, associated with their experience of waiting.

While the participants waited for a kidney transplant, they were attending the hospital for haemodialysis therapy three times each week. During this time, the nurses on the haemodialysis unit were the primary health care provider for these patients. More than any other health care provider, these nurses had the opportunity to provide information and support for the participants, while they waited for a kidney transplant. However, the participants' accounts emphasised that the nurses on the haemodialysis unit rarely communicated with them during their treatment. Consequently, the participants' experience of waiting, described in the themes *Lost Time* and *Waiting for a Kidney Transplant* was not recognised or addressed by these nurses. The participants' experience of communicating with the nurses will be discussed in the third and final theme labelled: *Communicating with Nurses: Myth versus Reality*.

¹⁰⁸ In the authentic mode of existence, I am aware of the finitude of my existence, but still project forward into possibilities in the originary future. In the inauthentic mode of existence, I do not acknowledge my finite nature. Instead, I allow myself to be absorbed in the everyday tasks and activities, which occur in world-time to avoid this realisation. The threefold structure of originary temporality remains unified in both modes of existence.

4.3 THEME 3 - COMMUNICATING WITH NURSES: MYTH VERSUS REALITY

Several of the participants described their inability to communicate with nurses during haemodialysis therapy. They indicated that the nurses on the haemodialysis unit were persistently busy, putting patients on and taking them off dialysis machines. The excessive throughput of patients meant the nurses rarely spent time talking or listening to the participants during their treatment. Indeed, the only time the nurses seemed to interact with the participants was to manage the technical and physical aspects of care. Therefore, the level of nurse-patient communication rarely progressed beyond a superficial or clinical level.

The participants' accounts illustrated that the absence of nurse-patient communication made them feel isolated and invisible. The superficial dialogue with the nurses effectively prevented the participants from expressing their unique experience of life on haemodialysis therapy. Therefore, the nurses did not recognise or respond to their experience of waiting, described in the previous themes.

The participants implied that they were dissatisfied with the shallow level of nurse-patient communication, which occurred during haemodialysis therapy. As a result, the distressing feelings of disappointment, isolation, irritation, frustration, and anger were both implicitly and explicitly expressed in their accounts.

For instance, in both interviews with Ali, he indicated that the nurses were too busy to communicate with him during haemodialysis therapy. The following account was taken from our follow-up interview. Ali implied that the number of patients requiring treatment meant the nurses did not have the time to stop and talk to him during treatment. Therefore, the only time the nurses approached him, was to respond to machine alarms.

Ali said:

They [the nurses] would come to you [during dialysis], but only if you wanted them...or they might pass by and they'd say "are you o.k?" but they wouldn't have time to stand and chat to you...they might for a minute or two...If the machine is beeping, they'll have to come then, but they just correct the machine and go again...they wouldn't have time to stand up here for ten minutes to chat to you...there's too many patients here, and normally there might be only two or three nurses on, so their time is taken up. (2/2)

Correspondingly, in the follow-up interview with Liz, she had received a kidney transplant one month previously. She recalled how the nurses had been too busy to talk to her during haemodialysis therapy. Occasionally they had been so busy, they failed to regularly monitor her blood pressure.

Liz recalled:

Sometimes you'd get to talk to the nurses, and other times they were so busy, they wouldn't have time even to check your blood pressure...They'd check it when you go on the machine and when you're coming off, but usually they'd check it once or twice during the dialysis...but some days they wouldn't have time, they'd be so busy...If someone was sick or that, they would be busy...they would come back and talk to you if they weren't busy. (15/2)

In both interviews with Alex, he illustrated the lack of nurse-patient communication, which existed on the haemodialysis unit. At the time of the follow-up interview, he had recently received a kidney transplant. He recalled how the nurses on the haemodialysis unit had been too busy to talk to him during treatment. Indeed, they seldom approached him, unless a technical or physiological complication occurred.

Alex recounted:

They [nurses] usually seemed to be busy enough...and I suppose with breaks and that there wouldn't be that many of them around...and they'd be usually putting someone on, or taking them off, or else they'd be doing reports...You could have several dialysis sessions and they wouldn't really come up to you and sit down and have a chat...that wouldn't really happen...the odd one might...If you felt weak or sick, they'd be all around you then! But lucky enough it [dialysis] went very straightforward for me during dialysis...I wasn't a major problem to them...If there was any problems, or if the machine started beeping, there'd be someone over to you. (3/2)

Beneath Alex's account was the irritation and frustration he felt toward the nurses for their repeated failure to communicate with him during dialysis.

Like Alex, Jeff also exemplified his inability to communicate with nurses on the haemodialysis unit. He described the attention he had initially received from the healthcare team when he commenced the treatment. At the time, Jeff had to have dialysis access formed, and frequently communicated and interacted with the healthcare team.

However, since Jeff had commenced haemodialysis therapy, he felt forgotten and abandoned. The nurses on the dialysis unit did not approach him during treatment unless his machine alarmed.

Jeff said:

The thing about dialysis...is when you start on it...and you're getting your permcath [dialysis line] fitted, you're getting your fistula done...and the next thing all that is done, and you're just left on dialysis then, and if there is nothing going wrong...it's not so much that you're forgotten about, but there is no one coming to you...If the machine doesn't beep, there is no reason for a nurse to be coming up to take your blood pressure...where if there is something wrong with you, there is always someone around...It would usually be a problem with the machine, it would be beeping, but the machine hasn't beeped at all now, it mightn't beep at all for the night, so there would be no one coming near you. (13/2)

Jeff's account conveyed his disappointment with the level of engagement and interaction he received from the nurses.

Similarly, Danny also highlighted his dissatisfaction and disappointment with the degree of nurse-patient communication on the haemodialysis unit. In the first interview with Danny, he expressed a need to talk to nurses and share his concerns about his illness and treatment. However, since the nurses rarely spoke to him during dialysis, his concerns were not acknowledged.

This was Danny's account:

They [nurses] sometimes come and have a chat...but then at times it's chaos, you get put on [the machine] and that's it, you don't get to speak to anybody for the whole shift...I accept there are staff issues, you can't expect people to sit down and spend half an hour chatting everyday, but it would be nice to be asked how you are getting on, and if you had any problems...You do feel a bit isolated at times...very few of them [nurses] have any comprehension of what it is like to be here on dialysis...the restrictions and the limitations...You really do need somebody, that you could pick up the phone and tell them you're problems. (7/1)

Danny's narrative implied that the nurses failed to recognise or understand his personal experience of being a patient on haemodialysis therapy. Embedded in his account were the feelings of irritation, frustration, and isolation, as he tried to grapple with the difficulties of life on haemodialysis therapy. Because of the isolation he had experienced, Danny recommended the need to have "somebody" to specifically attend to his interpersonal needs.

The follow-up interview with Danny signified that his situation had not changed. The nurses were still too busy to talk to him during his treatment. Indeed, they rarely approached him unless a physical or technical problem occurred during the treatment.

You might chat to somebody if they were passing to do your blood pressure...but not if everything is going well, or this thing [machine] is not bleeping or anything...You might have a little chat for two minutes, but then invariably somebody else is alarming and off they [nurses] go...Basically they get you sorted and they take off, so you don't really talk much to anybody. (7/2)

According to Elena, the nurses did not have the time to talk and listen to her concerns during dialysis therapy. Therefore, like Danny, she emphasised the need to have someone to address her questions about ESRD and haemodialysis therapy.

All the nurses do their best, and they can't spend minutes or hours just chatting to make you feel better...they have a job to do...I think it would be nice if there was a person who took care of that side of things, to follow it [care] through...like when you come to dialysis, you have a lot of questions, and you want to know what to do...They [nurses] write it down in the diary that you need to see a dietician or a doctor, but sometimes they never see it through. (10/1)

In the follow-up interview with Elena, I also asked if she had the opportunity to talk with nurses during her treatment and she replied:

No...they [the nurses] seem to be so intent on pressing the buttons on the machine, reading what it says...Like talking to somebody at the same time as they're doing something isn't a good idea either...because if they're [nurses] doing things and then they suddenly say "oh dear", and you think, "what have they done now?"...You know they've lost their concentration...so therefore you tend not to worry them too much about trivia until they've got it [machine] more or less set up. (10/2)

Like the other participants, Elena's account exemplified how the technological aspects of haemodialysis therapy took up all the nurses' time and attention. Therefore, she seldom had the opportunity to communicate with them during her treatment.

In the follow-up interview with Nancy, she had received a kidney transplant almost a year previously. She recalled the difficulty she had experienced while making the transition from life on haemodialysis, to life with a transplant. From Nancy's perspective, the nurses on the dialysis unit had been too busy to communicate with her during treatment. Consequently, she had received very little information or support while she waited for a kidney transplant.

You wouldn't get a chance [to talk to the nurses], they would be so busy...They would put you on the machine, but it was a basic "how are you today?" and I'd say "I'm fine", just very shallow conversation...You couldn't say "well, I really don't feel good", they hadn't time...If I was very sick, I'd say "oh God! I'm not well, I've been vomiting", and they'd say "we'll get the doctor over to you", and they would...that's it basically...It was always about your needles, or about the blood pressure, or about your medication...to do with your illness to a certain extent. (16/2)

Although Nancy had been on haemodialysis therapy for over four years, her conversation with the nurses did not seem to have progressed beyond a "clinical" level. Indeed, Nancy's account illustrated that the nurses rarely focused on anything beyond the technical and physical aspects of patient care. By specifically structuring the conversation with Nancy around these issues, it is suggested that the nurses essentially disregarded her distinctive experience of illness and treatment.

The participants' accounts implied that they were discontented with the superficial level of nurse-patient communication. Consequently, threaded throughout their narratives were the distressing feelings of disappointment, isolation, irritation, and frustration. For some participants, the persistent deficit in nurse-patient communication caused these distressing feelings to escalate to the level of anger, resentment, and hostility. This subsequently hindered the progression of a positive nurse-patient relationship.

For example, David spoke about the poor relationship he had with some nurses on the dialysis unit. Beneath David's account was his desire to be involved in decisions about his treatment and care. However, he insisted that some nurses refused to recognise or accept his unique knowledge of his illness. The lack of effective nurse-patient communication effectively prevented David from expressing his opinions about his treatment. Moreover, it hindered the development of a therapeutic nurse-patient relationship.

It may well have been the case, that the nurses were providing the most appropriate treatment for David. However, their failure to communicate in a concerned and caring manner meant that he viewed the nurses' approach as controlling rather than caring. Thus, he interpreted their requests as demands, and expressed his resentment, hostility, and anger towards the nurses.

In response, David challenged the control exerted by the nurses by refusing to adhere to the prescribed treatment regime. Each time he arrived for treatment, he specifically demanded that his treatment time of four hours, be reduced to three and half hours.

David recalled:

At the beginning [of dialysis] I found it very hard...there was no such thing as [nurses] being kind or nice to people or anything...but the good ones [nurses] made up for it...there is good ones [nurses]...but the other ones hate to be here, and if you see someone like that on the shift, you just don't like it...There is a few that think they're boss and that's it! Really boss, and you can say whatever you want to say, but they'll do what they want to do...But to be honest with you, I kick up [challenge the nurses] and they don't like me for doing it...I just say "I'm the patient, you're the nurse, and I don't want to do it that way, and you should look after me...Because it's no use doing something that you don't want to do. (9/2)

Chris also conveyed the absence of a positive relationship with the nurses on the dialysis unit. In the first interview with Chris, he stated that the nurses tended to separate patients who talked and interacted during dialysis therapy. I asked him why he felt the nurses did this, and he replied:

Well you'd have to know one or two of the patients that come in here in the morning [laughs]...sometimes you can't have them sitting beside each other because they argue...Also some of the nurses' personalities are different than others...I think it's just the luck of the draw...I don't think they [nurses] would do it [separate patients] on purpose. (6/1)

During my time collecting data on the haemodialysis unit, the nurses informed me that Chris was very disruptive during dialysis therapy. He continuously called and nagged different nurses throughout dialysis, repeatedly asking them the same questions about his treatment. Although the nurses tried to ignore him, Chris also created arguments with other fellow patients, which culminated in these patients also complaining to the nurses during treatment.

Therefore, Chris caused the arguments he referred to in his account. To limit the disruption caused by his behaviour, the nurses decided to situate him at a dialysis station at the far end of the unit. This way his ability to annoy other patients and nurses was limited.

In the follow up interview with Chris, he highlighted his growing suspicions that the nurses were deliberately isolating him during treatment in order to keep him quiet. Embedded in his account was a sense of disappointment and frustration that he was being deliberately ignored by the very people who were supposed to care for him.

Chris said:

I'm usually surrounded by older women that don't talk, and they just go to sleep...It depends on the nurses that are on at night and how they assign the beds...I don't know...they [nurses] seem to think I talk too much...I don't know why it happens [that he is segregated] but it still happens...Really I don't talk, I don't know why some nurses do it...Sometimes I feel like I'm being isolated...I'm used to it now [sighs] because they're [nurses] always doing it...But I talk to some of those old guys down there because they're the only people that talk, none of the other people talk, they go to sleep, they normally don't talk much, and it depends who [which nurse] is on the night shift I guess...Some nurses would like everything to be quiet with not much talking going on. (6/2)

4.3.1 DISCUSSION OF THEME

The existing literature repeatedly supported the view that communication was a fundamental part of nursing, and was essential in the development of an effective nurse-patient relationship (Peplau, 1992; Arnold & Boggs, 1995; Peplau, 1997; Attree, 2001; Mc Cabe, 2004). Considering that the participants attended dialysis three times each week, it seemed reasonable to suggest that the nurses working in this area should be able to spend some time communicating with these individuals. However, as the narratives above pointed out, the participants rarely had the opportunity to communicate with nurses during their treatment. The participants' descriptions of communicating with nurses will now be discussed in relation to the existing literature on the person's experience of ESRD and haemodialysis therapy.¹⁰⁹

The nurses on the haemodialysis unit seemed to be relentlessly busy. As a result, they did not spend sufficient time talking and listening to the participants during treatment. A qualitative study by Faber, De Castell & Bryson (2003) also demonstrated that some healthcare providers rarely spent time engaging in social interaction with patients during haemodialysis therapy. The four participants in the study had been dialysing in the same ward, with many of the same health care providers for months or years. Despite this, the researchers noted that very little social interaction occurred between the people on dialysis and the healthcare providers. In fact, healthcare providers tended to perform their work, without any engagement with the person who was receiving care. From the researchers' perspective, it was almost unbelievable that people spent so much time together, and yet had such minimal social contact. However, they contended that the increased throughput of patients on dialysis, limited the amount of time available for healthcare providers to interact with each person.

The participants in my study emphasised that the nurses were too busy to communicate with them during haemodialysis therapy. The only time the nurses attended to them was to manage the technical and physical aspects of care.¹¹⁰ Consequently, the nurses tended to structure their communication with the participants specifically around these issues.

¹⁰⁹ This theme will also be discussed in relation to a broader body of literature in Chapter 5: *Discussion of the Findings*.

¹¹⁰ For example, see the accounts of Ali (p206), Alex (p206), Elena (p 208-209) & Danny (p207-208).

However, this meant that the level of nurse-patient communication rarely got beyond a superficial or clinical level.

Other authors have conveyed how the high turnover of patients on the haemodialysis unit, created a situation where the nurse primarily concentrated on the technical and physical features of care (Bevan, 1998; Sloan, 2002). For instance, Bevan (1998) compared the excessive throughput of patients on the haemodialysis unit to “a conveyor belt or production line of patients for treatment” (p732). From the author’s viewpoint, the busyness on the haemodialysis unit meant the nurses’ attention was predominantly focused on the technological aspects of patient care. However, this narrow focus created a situation where the nurse merely managed the machine and the patient in an “unseeing, ritualised manner” (p734).

Correspondingly, the study by Sloan (2002) suggested that haemodialysis units were run on schedules similar to major airports, where people continuously arrived and departed from a specific dialysis chair. The nurse essentially viewed her role as confined to the management of the technologies of the treatment. Sloan confirmed that the pressure for reduced healthcare costs and efficiency, decreased the amount of time healthcare providers spent with patients. Consequently, the management of the dialysis machine absorbed most of the nurse’s attention, while the patient slipped into the background. Sloan’s (2002) study reported how the nurses’ technological focus created a breakdown in their ability to communicate and care. As a result, several of the participants in the study felt invisible.

The participants in my study implied that the lack of nurse-patient communication made them feel isolated and invisible. The depth of conversation with the nurses was not sufficient to allow the participants to convey their unique experience of life on haemodialysis therapy. Hence, they expressed a desire to have a designated person who would provide the necessary levels of interpersonal care, which would allow their concerns to be addressed.¹¹¹

¹¹¹ For example, see the accounts of Jeff (p207), Danny (p207-208), Elena (p208-209) & Nancy (p209).

These findings were corroborated within the existing literature related to the person's experience of ESRD and haemodialysis therapy. For instance, the study by Hagren et al (2005) contended that a sense of emotional distance existed between the healthcare providers and the participants in the study. The participants signified that the nurses did not understand or respect their life situation. As a result, they emphasised the need to have healthcare providers who would provide person-centred care.

Similarly, the participants in the study by Nagle (1998) articulated their desire to be recognised as a unique person with individual needs. They required this level of personalised care to overcome the threat of depersonalisation posed by the technology of dialysis. They felt they knew their situation better than the healthcare providers, and wanted this knowledge to be incorporated into decisions about their care. Despite their constant efforts to be heard, several participants stated that the nurses failed to recognise or accept their wishes regarding their care.

Like these participants, the narrative account of David also verified that the nurses refused to accept his opinions about his treatment and care.¹¹² As a result, David refused to adhere to his prescribed treatment regime, in an effort to exert some control over the situation. It is suggested that the lack of nurse-patient communication, illustrated in my study may have also prevented the nurses from recognising the participants' unique and personal experience of life on haemodialysis therapy. Consequently, their experience of waiting was not recognised or acknowledged by these nurses.

For example, the participants' accounts implied that the nurses did not acknowledge their distressing experience of killing time, while they waited impatiently for the treatment to end.¹¹³ This was reflected in the environment of the haemodialysis unit, as there was nothing provided for the participants, which would help them to pass the time. Moreover, the inappropriate placement of haemodialysis machines, and the random allocation of patients to dialysis spaces, prevented communication between patients during treatment.¹¹⁴

¹¹² See page 210 for David's account.

¹¹³ See page 133 for the sub theme *Killing Time*.

¹¹⁴ For example, see the accounts of Ali (p134), David (p141), Donna (p139) & Elena (p140).

According to McCabe (2004) communicating with nurses was an effective way for patients to pass the time when they were in hospital. However, the absence of nurse-patient communication on the dialysis unit meant the participants were unable to use this strategy to pass the time during their treatment. It also seemed that the lack of effective nurse-patient communication might have also caused the nurses to disregard the participants' experience of waiting, described in the sub theme *Wasting Time*. If we recall, the participants described their experience of wasting time, having to wait for dialysis machines, hospital taxis, and doctors.¹¹⁵ The participants' accounts indicated that the nurses on the haemodialysis unit did not acknowledge their experience of wasting time.¹¹⁶

For instance, some participants emphasised how the nurses essentially overlooked their experience of having to repeatedly wait for haemodialysis machines to become available.¹¹⁷ In addition, the nurses did not appear to recognise the participants' distress caused by waiting for hospital taxis. While the nurses on the unit had the ability to deal with these avoidable and unnecessary delays, it seemed this did not occur. Therefore, some participants were forced to organise their own transport to and from the hospital, to avoid wasting time.¹¹⁸

The participants' experience of waiting for a kidney transplant also appeared to be overlooked by the nurses on the haemodialysis unit. The sheer lack of nurse-patient communication meant the nurses failed to recognise the participants' concerns and uncertainties surrounding the process of transplantation. Therefore, the necessary follow-up information and support was not provided for the participants throughout the waiting time.¹¹⁹

Because of the deficient levels of follow-up information and support, it seemed the nurses never corrected the participants' unrealistic expectations about kidney transplantation. Hence, the participants continued to live in hope, because they viewed haemodialysis therapy, as a temporary problem. However, when the "expected" date for

¹¹⁵ See page 144 for the sub theme *Wasting Time*.

¹¹⁶ For example, see the accounts of Harrison (p145), Alex (p146), Eleana (p148) & David (p149).

¹¹⁷ For example, see the accounts of Harrison (p145), Alex (p146), & Gloria (p146).

¹¹⁸ For example, see the accounts of Carl (p151) and Jeff (p151).

¹¹⁹ For example, see the accounts of Jeff (p179), Danny (p180), David (p182), Nancy (p183).

a kidney transplant passed, they became increasingly uncertain. When confronted with uncertainty, the initial trust the participants had in the nurses was challenged. They began to question the fairness of the waiting process and the honesty of the healthcare team.

Similarly, the participants in the study by Weems & Patterson (1989) also “figured” a potential time by which they hoped to receive a kidney transplant. They based this time frame on the numerical information they had received from the healthcare team. However, when they failed to receive a kidney transplant within this duration, some participants began to question the rules of selection. Their optimistic outlook of transplantation was diminished, as the participants began to wonder if their names were still on the list, or if they had been forgotten.

Correspondingly, the men in the study by Polaschek (2000) also interpreted haemodialysis therapy, as a provisional treatment until they received a kidney transplant. They were convinced that they would definitely receive a transplant, and that it would be “successful”. According to Polaschek (2000), the unrealistic expectations about transplantation held by the participants, merely reflected the dominant discourse of the healthcare professionals working in the area.

The participants in my study presented a similar experience to those in the study by Polaschek (2000). For instance, at the time of the participants’ diagnosis with ESRD, the healthcare team informed them of the average waiting time for a kidney transplant. While this information offered hope at a difficult time, it was also essential that the participants were made aware that the average waiting time was a provisional timeframe. However, the participants’ accounts illustrated that they misinterpreted the information they received from the healthcare team. They understood ESRD and haemodialysis therapy to be short-term problems, which would be alleviated by a transplant. Because of this unrealistic view, the participants were ill prepared for the complexities of life with a chronic illness.

While it was acceptable for the healthcare team to inform the participants of the average waiting time for a kidney transplant, it was also essential that they informed them of the

chronic nature of their illness. Moreover, the participants should have received ongoing information and support to enable them to come to terms with life on dialysis therapy.

As mentioned previously, the participants regularly interacted with the nurses on the haemodialysis unit, while they waited for a kidney transplant. Therefore, it would seem reasonable to suggest that these nurses should have provided the necessary ongoing information and support required by the participants. However, the absence of nurse-patient communication meant the nurses neither acknowledged or addressed the participants' needs for information and support. As a result, the nurses disregarded the participants concerns and uncertainties about kidney transplantation.

The participants in the study Sloan (2002) also indicated that the concerns they had in relation to their illness and treatment went largely unrecognised by the healthcare providers. Sloan contended that the participants' accounts represented a story of breakdown, where healthcare providers became inattentive and insensitive to the patients' needs.

For instance, the healthcare providers often chastised participants for their non-compliance with the dietary and fluid restrictions, yet failed to respond to the positive efforts they were making. Moreover, the participants' accounts were replete with examples of how oppressive labels negatively shaped their experiences of ESRD and dialysis therapy. It seemed that the healthcare providers concentrated on the development of self-care behaviours amongst patients. These behaviours were deemed to result in positive outcomes with the dialysis treatment regime. Therefore, the participants who were unwilling and/or unable to engage in these behaviours were labelled as "bad patients", "non-compliant", "passive", or "unmotivated" to help themselves (Sloan, 2002).

This unnecessary labelling of patients was illustrated in the narrative accounts of Chris.¹²⁰ It seemed that Chris's failure to abide with the behavioural norms on the haemodialysis unit, resulted in him being labelled a "disruptive" patient. Therefore, he was allocated a dialysis space that was away from the nurses' station, and isolated from

¹²⁰ See page 211 for Chris's account.

patients who would talk to him during treatment. Chris's disruptive behaviour was deemed by the nurses to warrant this type of segregation. However, as a result of the inappropriate level of nurse-patient communication, the nurses failed to address the underlying cause of Chris's behaviour.

Both interviews with Chris were conducted during his treatment. Afterwards the nurses expressed their surprise that he had controlled his disruptive behaviour for the duration of the interview. From my perspective, it appeared that Chris was very grateful to have someone to talk and listen to him during haemodialysis therapy. Indeed, the distress caused by his ongoing experience of waiting was illustrated in the sub themes *Killing Time*, *Uncertainty*, and *Being on Hold*.¹²¹ However, the labelling of Chris as disruptive meant his experience was effectively silenced in his superficial dialogue with the nurses.

Similarly, in the study by Sloan (1996), which explored the medical treatment decisions for ESRD patients in the USA, an overarching pattern called "Illness as lived in structured silence" was developed. This theme referred to the social barriers to dialogue that existed between the participants and their care providers. The effect of "labelling" was described as a significant feature, which led to the silencing of nurse-patient communication in relation to transplantation. Some participants claimed they were considered unsuitable for transplantation because the healthcare team had labelled them "too old", "non compliant" or "unappreciative".

These labels created a situation where the conversation about transplantation was silenced between the healthcare providers and the participants. Thus, the participants did not get to speak to anyone about transplantation, and had no option but to remain on dialysis. Like these participants, the labelling of Chris as a disruptive patient by the nurses on the haemodialysis unit meant his distressing experience of waiting was silenced. Therefore, he expressed his disappointment at the insufficient level of nurse-patient communication.

¹²¹ See pages 141, 183, and 185 for Chris's accounts of killing time, uncertainty, and being on hold.

Like Chris, the other participants in my study implied that they were also unhappy with the superficial level of nurse-patient communication. The distressing feelings of disappointment, frustration, resentment, animosity, and anger were interweaved within their narratives. For some participants, the unacceptable level of nurse-patient communication was difficult to tolerate on an ongoing basis. Therefore, the distressing feelings seemed to escalate for these participants. It is suggested that the persistent deficit in nurse-patient communication may have created a barrier to the development of a positive relationship between the participants and the nurses.

The literature conveyed that effective communication was required for the development of a positive nurse-patient relationship (Peplau, 1992; Fosbinder, 1994; McCabe, 2004). These authors also emphasised that a positive nurse-patient relationship was necessary for high quality, patient-centred care. Various studies, which explored the person's experience of ESRD and dialysis, also commented on the importance of a positive nurse-patient relationship.

For instance, the participants in the study by Sloan (2002) highlighted how the caring practices of some nurses enabled them to overcome their experience of being depersonalised by the environment of the haemodialysis unit. The willingness of these nurses to spend time with the participants specifically facilitated their ability to come to terms with their illness and treatment. Moreover, these concerned and caring behaviours made the participants' feel "valued", "at home" and "safe" (Sloan, 2002).

Correspondingly, the study by Rittman et al (1993) identified a theme entitled "dwelling in dialysis". The theme referred to the participants' experience of living with, and being "at home" in the dialysis unit. The relationship of the participants with the nurses was an integral part of this theme. The participants spent many hours each week with the nurses, and had come to view the dialysis unit as home.

The findings conveyed that the nurses recognised and affirmed the significance of the participants' experience of living on dialysis. In particular, they recognised the sense of ownership the participants had of "their space" on the unit. For example, the participants became attached to the objects in their space during dialysis therapy. They wanted to use the same chair, dialysis machine, and television during each visit. Any change in machines, schedules, or allocated place in the unit was interpreted as a loss by the participants. According to the researchers, the nurses' ability to recognise and understand the participants' connection with their space on the dialysis unit, served to counter the dehumanising effects of the dialysis technology.

The participants in the study by Gregory et al (1998) indicated that nurses' continuous presence on the haemodialysis unit made them the most ongoing and reliable source of emotional and psychological support. The nurses were appreciated for their caring attitude, their ability to accept the patient as a person, and their ability to make the patient feel comfortable. Their willingness to spend time with the participants and address their questions and concerns were also deemed important. According to the authors, the caring nature of these nurses served to enhance the participants' adjustment to dialysis therapy.

Conversely, it seemed that the lack of nurse-patient communication, described by the participants in my study, essentially hindered the development of a positive nurse-patient relationship. According to Thorne & Robinson (1989), there were three distinct stages in the patient-healthcare provider relationship: the naive trust stage, the disenchantment stage, and the guarded alliance stage. The authors indicated that most chronically ill patients had unrealistic expectations that medicine would provide a "cure" for their illness. As a result, these patients entered into a relationship with healthcare providers based on "naive trust".

However, when the reality of the long-term nature of chronic illness was realised, this trust was unavoidably shattered. Thus, the person entered the "disenchantment" stage of the relationship with healthcare providers. Within this stage, the breakdown of trust typically resulted in feelings of dissatisfaction and animosity amongst the patients. Eventually this unpleasant stage in the relationship improved through a form of "guarded alliance". Guarded alliance referred to the various new kinds of relationships

with healthcare providers, which served to accommodate the patients' ongoing dependence on their services (Thorne & Robinson, 1989).

A study by Sloan (1999) demonstrated the presence of all three stages in the nurse-patient relationships of individuals with ESRD. The findings illustrated that in the early days of treatment, the relationship of some participants with the nurses was based on "naive trust". The participants believed in the nurses' sincerity and competence to manage their health problems. However, as setbacks inevitably occurred in the illness trajectory, the relationship progressed into the "disenchantment" stage.

The nurses' failure to respond or understand the needs of the participants fuelled the disenchantment stage of the nurse-patient relationship. The participants tended to view the physical setbacks as evidence of incompetence or lack of interest on behalf of the nurses. They were angry about the chronic nature of their disease and the apparent futility of medicine to resolve their problems. The unavoidable necessity for treatment meant the participants relied on the nurses for their continued support. This dependence forced the participants and the nurses to interact. The interaction moved the nurse-patient relationship into the "guarded alliance" stage (Sloan, 1999).

Based on the length of time that the participants in my study spent with the nurses, one would expect the nurse-patient relationship to have reached the "guarded alliance" stage, presented by Thorne & Robinson (1989). However, it is suggested that the absence of effective nurse-patient communication prevented the participants' relationship with the nurses from progressing beyond the "disenchantment" stage.

To re-iterate, the disenchantment stage typically culminated in feelings of dissatisfaction and animosity amongst patients (Thorne & Robinson, 1989). In my study, the participants' accounts of communicating with the nurses implied that they were dissatisfied with the nurses' level of engagement. Consequently, the distressing feelings of isolation, frustration, animosity, and anger were both implicitly and explicitly expressed in their accounts.¹²²

¹²² For example, see the accounts of Danny (p207-208), David (p210), and Chris (p211).

4.3.2 SUMMARY OF THEME

This theme discussed the participants' experience of communicating with the nurses on the haemodialysis unit. Their accounts implied that the nurses were too busy to communicate with them during dialysis therapy. Instead, the nurses confined their attention to the technical and physical aspects of care.

This superficial level of nurse-patient communication meant the nurses failed to acknowledge the participants' distinctive experience of living on haemodialysis therapy. As a result, the participants felt isolated and invisible. Moreover, their experience of waiting, described in the themes *Lost Time* and *Waiting for a Kidney Transplant* was not acknowledged or addressed by the nurses.

The participants' accounts conveyed that they were dissatisfied with the inadequate level of nurse-patient communication. Therefore, the distressing feelings of disappointment, isolation, irritation, and frustration were palpable throughout their narratives. For some participants, the ongoing failure of the nurses to engage in appropriate levels of communication caused these distressing feelings to intensify to the level of anger, resentment, and hostility. This subsequently created a barrier to the development of a positive nurse-patient relationship.

4.3.3 CONCLUDING COMMENTS

Within this chapter, the findings of the study were discussed. The experience of waiting was identified as a constitutive pattern in the study. The pattern consisted of three themes: *Lost Time*; *Waiting for a Kidney Transplant*, and *Communicating with Nurses: Myth versus Reality*.

The theme *Lost Time* referred to the excessive time spent waiting when the participants attended haemodialysis therapy. The time spent waiting prevented the participants from engaging in everyday activities, and was interpreted as lost time. The theme *Lost Time* was constituted by two sub themes: *Killing Time* and *Wasting Time*. The participants described their struggle to kill time while they waited for haemodialysis to end. They

also described their experience of wasting time waiting unnecessarily before and after haemodialysis therapy. The experience of repeatedly waiting seemed to culminate in the existential mood of boredom, depicted by Heidegger (1995).

The theme *Waiting for a Kidney Transplant* was also presented in this chapter. The theme consisted of three sub-themes: *Living in Hope*, *Uncertainty*, and *Being on Hold*. The participants described their experience of living in hope, while they waited for a kidney transplant. However, as the wait for a transplant continued without an endpoint in sight, they became uncertain. The uncertainty of waiting indefinitely for a kidney transplant meant the participants were unable to contemplate possibilities for the future. In addition, the restrictions of life on haemodialysis effectively hindered them from participating in their everyday activities. Therefore, they described their experience of being on hold, while they waited for a kidney transplant. It was suggested that the participants' relentless experience of waiting for a transplant resulted in the existential moods of anxiety and boredom, described by Heidegger (1962, 1995).

The superficial level of nurse-patient communication on the haemodialysis unit meant the participants' experience of waiting was not recognised by the nurses. Therefore, the nurses did not attend to the participants' experience of waiting. This lack of nurse-patient communication was discussed in the third and final theme titled *Communicating with Nurses: Myth versus Reality*. In the following chapter, the three themes, which constituted the participants' experience of waiting, will be discussed in relation to the existing literature.

CHAPTER 5 : DISCUSSION OF THE FINDINGS

This chapter provides a discussion of the findings. The participant's accounts of waiting will be discussed in terms of the existing literature. The discussion of the findings consists of two sections. In the first section, titled "Insights from the nursing literature", the participant's experience of waiting will be discussed in relation to the concept of enduring, advanced by Morse (2001).

If we recall, the participants' experience of waiting culminated in the existential moods of anxiety and boredom. These moods highlighted the finitude of existence to the participants and prompted them to live in either an authentic or inauthentic mode of existence. However, the relentless and repetitive nature of their experience of waiting meant the participants failed to live in either mode of existence. The inability to live in either mode of existence in response to anxiety and boredom created a disconnection in temporality. Moreover, it culminated in distressing moods for the person.¹²³

It is proposed, that the disconnection in temporality and the intensification of distressing moods, illuminated within the participants' experience of waiting, were depicted in the concept of "enduring", advanced by Morse (2001). From Morse's perspective, the concept of enduring was based on a primarily psychological framework. Hence, the experience of enduring was viewed as a cognitive or subjective state, which culminated in a series of emotional and behavioural responses.

Conversely, the participants' accounts in the study highlighted that their experience of waiting did not merely consist of a psychological response, which resulted in various emotions and behaviours. Instead, their experience of waiting was a constitutive feature of their existence or their "being-in-the-world". However, these existential features, which formed the basis of the participants' experience of waiting, were not incorporated into Morse's (2001) concept of enduring. Hence, there was a need to expand and refine the concept in order to address this conceptual gap.

¹²³ See pages 127-128 for the previous discussion on the person's inability to live in either mode of existence.

By incorporating characteristics of Heidegger's existential perspective of temporality and mood with Morse's (2001) concept of enduring, a model of enduring was formulated to provide a more comprehensive description of the participants' experience of waiting. This will be discussed in the second section of this chapter titled "Insights from the nursing literature".¹²⁴

According to Morse (2001), the person who was enduring required nursing care to be patient-centred. The nurse was required to spend enough time with the patient to allow him/her to recognise and respond appropriately to the person's experience of enduring. This personal knowledge of the patient was essential if therapeutic nursing interventions were to be provided.

In contrast, the participants' accounts in my study indicated that care on the haemodialysis unit was not patient-centred. In particular, the theme *Communicating with Nurses: Myth versus Reality* clearly illustrated this point. It is proposed, that the context of care on the haemodialysis unit may have been responsible for the absence of patient-centred care. This suggestion will also be discussed in the second section of this chapter titled "The context of care on the haemodialysis unit".

¹²⁴ Refer to Appendix E (p313) for a further discussion of the participants' experience of waiting in relation to the existential literature of Samuel Beckett and Franz Kafka.

5.1 INSIGHTS FROM THE NURSING LITERATURE

It is proposed that Morse's (2001) concept of "enduring" encapsulated the participants' experience of waiting, advanced in the study. As mentioned in the literature review, Morse (2001) described suffering as a response to loss, such as the loss of self, the loss of health, the loss of an anticipated future, and the loss of another. There were two behavioural states, which constituted her model of suffering: "enduring" and "emotional suffering".

Morse (2001) signified that emotional suffering was a very distressed state where emotions were released. Conversely, the state of enduring involved the cognitive suppression or blocking of emotions. Enduring was a strategy that allowed the person to "get through" an unbearable situation (Morse & Carter, 1995, 1996; Morse, 2001). The person who was enduring focused primarily on the present. However, within this present-oriented state, the person essentially blocked out the past and future (Morse, 2001).

Morse (2001) illustrated that suffering was not a linear process. Instead, the person oscillated back and forth between the states of "enduring" and "emotional suffering" before eventually moving onto the reformulated self. According to Morse (2001), the distressing emotional responses varied in intensity when the person was enduring. However, when these emotional responses became too intense to suppress, it resulted in a failure to endure and the person moved into emotional suffering. After slightly moving into the state of emotional suffering, some individuals perceived that they might psychologically disintegrate due to an overwhelming release of unpleasant emotions. Hence, after temporarily sensing emotional suffering, they quickly moved back into enduring.

This back and forth oscillation between enduring and emotional suffering repeatedly occurred until the person acknowledged that the loss or unbearable event had occurred. It was this acknowledgement that enabled the person to move into emotional suffering. Morse (2001) claimed that the person had to enter the state of emotional suffering

before s/he accepted the lost past and the altered future. Once the person achieved acceptance, s/he overcame suffering and moved onto the “reformulated self”.

Within the work of Morse, there appeared to be an underlying assumption that the person moved back and forth between the suppression and release of distressing emotional responses, before automatically moving onto the reformulated self. Indeed, this assumption was also embedded within the existing literature related to the person’s experience of ESRD and dialysis therapy. This literature illuminated a dynamic movement between distressing and positive emotional responses, which eventually resulted in the transformation of the self. However, like Morse’s work, this literature did not sufficiently address what would happen in the event of the person getting “stuck” in either emotional suffering or enduring.

This seemed to be precisely what happened to the participants in my study. Their accounts emphasised that they were unable to overcome the persistent experience of waiting. Hence, they were subsequently unable to escape the experience of enduring. It is proposed that the inability to escape from enduring culminated in the existential moods of anxiety and boredom, described by Heidegger (1962).

Unlike the existential perspective of Heidegger (1962), Morse’s (2001) concept of enduring was primarily based on a psychological perspective. Based on Morse’s (2001) interpretation, enduring was viewed as a cognitive or subjective state, which initiated a series of emotional and behavioural responses. In contrast, the participants’ accounts in my study highlighted that their experience of waiting did not merely consist of a psychological response, which resulted in various emotions and behaviours. Instead, their experience of waiting was a constitutive feature of their existence or “being-in-the-world”.

These existential features, which formed the basis of the participants’ experience of waiting, were not incorporated into Morse’s (2001) concept of enduring. Hence, there was a need to expand and refine the concept in order to address this conceptual gap. By incorporating characteristics of Heidegger’s existential perspective of mood and temporality with Morse’s (2001) concept of enduring, it was anticipated that a more appropriate description of the participants’ experience of waiting would be formulated.

5.1.1 TOWARD A MODEL OF ENDURING

Through the amalgamation of Heidegger's existential perspective with Morse's (2001) concept of enduring, a new "model of enduring" was formulated to provide a more comprehensive description of the participants' experience of waiting. A diagrammatical representation of this model is illustrated in Figure 2 (p232).

It is proposed, that because of the participants' experience of persistently waiting, described in the themes *Lost Time* and *Waiting for a Kidney Transplant*, they were unable to escape the experience of enduring. This culminated in the existential moods of anxiety and boredom, depicted by Heidegger (1962, 1995). These moods illuminated the possibility of death to the participants, which prompted them to live in either an authentic or inauthentic mode of existence. However, the ongoing nature of the experience of waiting meant that many of the participants were unable to live in either mode of existence. Consequently, they experienced an intensification of distressing moods and a disruption in the threefold structure of originary temporality.

These features of the participants' experience of waiting epitomised specific characteristics of Morse's (2001) concept of enduring. Within the following discussion, the proposed model of enduring outlined in Figure 2 (p232) will be used as a framework or scaffolding to describe the participants' experience of waiting.

As previously mentioned, the participants described their experience of living in hope, while they waited for a kidney transplant. The participants' accounts of living in hope indicated that they predominantly focused on clock and calendar time. By focusing on clock/calendar time, they were able to get through the days, weeks, months, and years spent waiting for a kidney transplant. In particular, the participants' believed they would receive a transplant within a specific time frame. This expectation contributed to their concentration on clock/calendar time.

Morse & Doberneck (1995) described a “determination to endure” as a universal component of hope, which allowed hope to be sustained. The authors stated that a significant time elapsed between the person selecting and attaining a goal. While the person was hopeful, s/he had to wait and endure the time lapse until the goal was attained (Morse & Doberneck, 1995; Morse & Penrod, 1999).

According to Morse (2001) and Morse & Carter (1996) enduring was a response that occurred when one had no choice but to get through an unbearable situation. When enduring, the person focused on the present and it was this focus that kept him/her going minute by minute. The person developed strategies to physically “hold on” to the present, such as watching the clock or counting something. However, this predominant focus on the present meant they blocked out the past and the future.

It is suggested that the description of watching the clock, presented in the participants’ accounts of living in hope, was depicted in the description of enduring by Morse and colleagues. The participants predominantly focused on clock time while they waited for a kidney transplant. Like Morse’s description of enduring, it seemed that the participants’ concentration on the “nows” of clock time effectively blocked off the past and future. However, the interpretation of time, which formed the basis of the participants’ experience, was not the largely psychological or cognitive interpretation of time, embedded in Morse’s concept of enduring. Rather, it was Heidegger’s (1962) perspective of ordinary or clock time, which formed the basis of the participants’ experience of living in hope. Moreover, Heidegger’s interpretation of time offered a more comprehensive explanation as to why the past and future were essentially blocked out when the person concentrated on clock time.

If we recall, Heidegger (1962) claimed that we did not normally understand time in terms of the endless sequence of “nows” of clock or ordinary time.¹²⁵ In contrast, we normally understood clock time in relation to the activities we performed in the world on a daily basis. World-time referred to the time used to structure and coordinate these everyday activities. Therefore, this perspective of time formed the contextual basis or background to ordinary or clock time. Since world-time constituted the originary

¹²⁵ See page 102 for the previous discussion on ordinary or clock time.

present, it was also embedded in the threefold structure of originary temporality. This meant that the threefold structure of originary temporality formed the core of both world-time and ordinary or clock time. However, as Heidegger (1962) pointed out, when the person merely focused on the endless sequence of “nows” of clock or ordinary time, this contextual background was concealed or covered over.

In other words, by focusing on the present “now” of ordinary or clock time, the past and future of originary temporality, which constituted its base, was effectively blocked out. By re-interpreting Morse’s concept of enduring in terms of Heidegger’s perspective of time or temporality, it was possible to understand the participants’ experience of living in hope as enduring. By focusing only on the present “nows” of clock time, while they initially waited for a transplant, the participants effectively overlooked the originary past and future, which provided its contextual base.

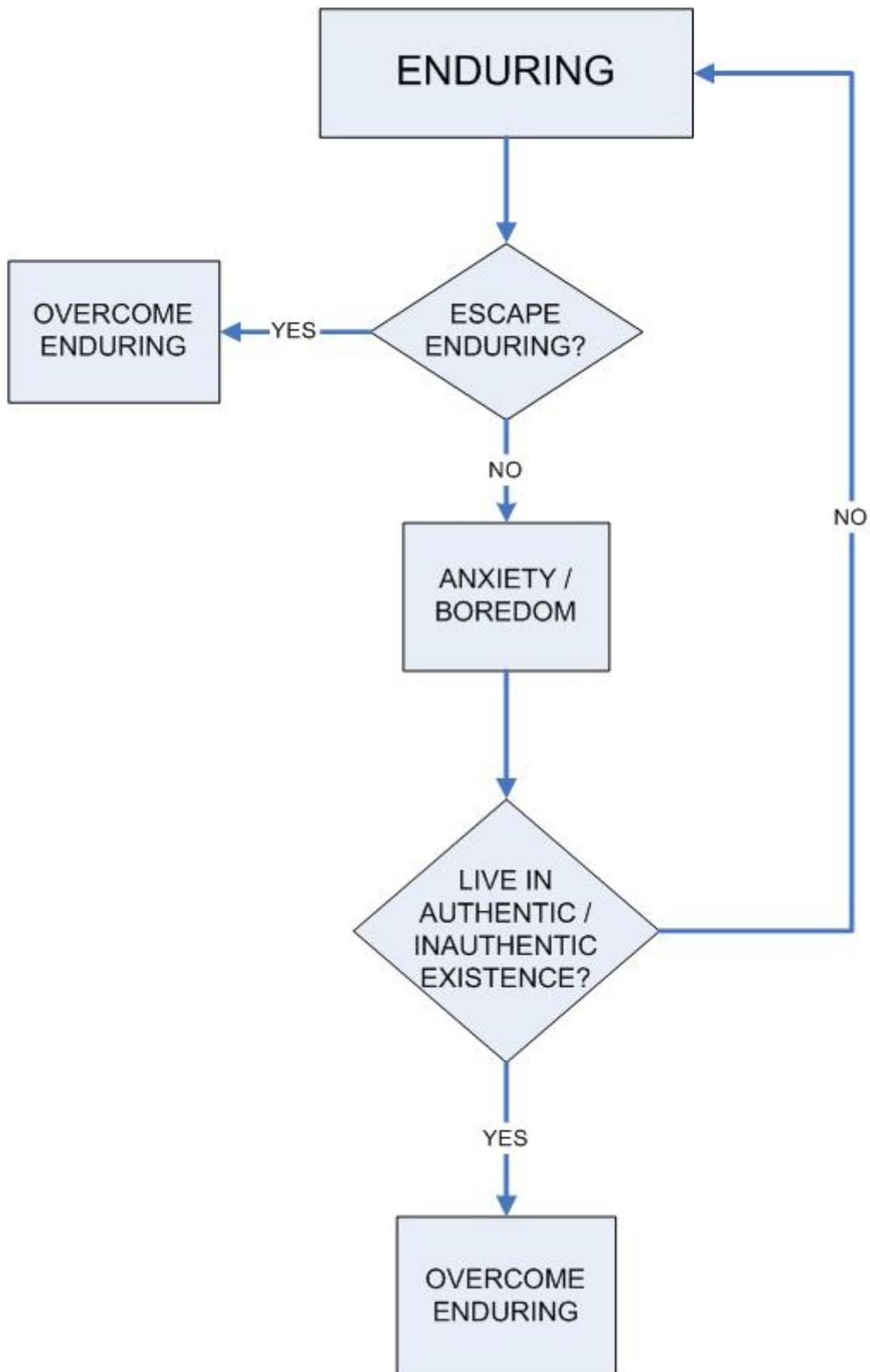
It is proposed that the relentless nature of the participants’ experience of waiting meant they were unable to escape from enduring. Thus, when the wait for a kidney transplant continued well beyond their expectations, the participants’ experience of living in hope turned to uncertainty. Because of uncertainty, they began to realise that haemodialysis therapy might not be the short-term problem they had initially anticipated. Thus, their experience of uncertainty culminated in uneasiness, sadness, disappointment, and depression.

The acceleration of distress, which accompanied the participants’ experience of uncertainty, was incorporated in Morse’s (2001) description of enduring. Morse (2001) emphasised that enduring involved the suppression of unpleasant emotions. However, she subsequently implied that when individuals were enduring, their emotional levels could change in intensity. For instance, there were times when emotional suppression occurred without the person even being aware (Morse & Penrod, 1999; Morse, 2001). Conversely, on other occasions it took a great deal of energy for the person to suppress their distressing emotions. As a result, the distressing emotions increased in intensity while enduring (Morse & Penrod, 1999; Morse, 2001).

As previously mentioned, Morse and colleagues interpreted enduring as a cognitive or subjective state, which initiated emotional and behavioural responses. Therefore, the intensification of distress, which occurred when one was enduring, referred to “emotional” or “psychological” distress. Unlike Morse’s perspective, the distress experienced by the participants while they waited for a kidney transplant, was not merely a psychological response. For instance, they did not describe their experience of uncertainty as an emotional reaction. Rather, the characteristic features of the participants’ experience of uncertainty symbolised Heidegger’s (1962) description of anxiety.¹²⁶ Hence, this implied that the failure of the participants to escape from the experience of enduring created existential anxiety (see Figure 2, p232).

¹²⁶ See page 125 for the previous discussion on the fundamental existential mood of anxiety.

FIGURE 2. MODEL OF ENDURING



According to Heidegger (1962), anxiety and boredom were fundamental existential moods. Therefore, to provide a thorough understanding of the participants' experience of uncertainty, there was a need to supplement Morse's (2001) psychological perspective of emotion with Heidegger's existential perspective of mood. If we recall, Heidegger's (1962, 1995) notion of mood did not refer to the predominantly psychological perspective of feelings or experiences. Instead, mood or attunement was described as a product of existence and arose out of being-in-the-world.¹²⁷

As a fundamental existential mood, anxiety highlighted the threefold structure of originary temporality to the person. This disclosed death as a possibility of the person's future. When confronted with the finitude of their existence, the participants were prompted to live in either an authentic or inauthentic mode of existence.¹²⁸ However, their accounts of uncertainty suggested that as a result of waiting indefinitely for a transplant, they were unable to live in either mode of existence.

Heidegger (1962, 1995) claimed that the inability to live in either mode of existence was responsible for the unpleasant and distressing moods we experienced on an everyday basis. Hence, it was proposed that the participants' inability to live in either mode of existence resulted in the distressing moods, which accompanied their experience of uncertainty. Moreover, the indefinite nature of the participants' experience of waiting for a kidney transplant meant they were persistently unable to live in either mode of existence, which caused the distressing moods to intensify.

If we recall, Morse (2001) indicated that the distressing emotions varied in intensity when the person was enduring. However, using Heidegger's (1962, 1995) interpretation of mood, we were able to provide a more fitting description of the distressing moods, which accompanied the participants' experience of uncertainty. It is suggested that the participant's inability to live in either an authentic or inauthentic mode of existence, while they relentlessly waited for a transplant, meant they were unable to overcome the

¹²⁷ See pages 123-124 for the previous discussion on Heidegger's notion of mood.

¹²⁸ In the inauthentic mode of existence, Dasein absorbs itself in everyday activities to avoid reflecting on its death and finitude. In the authentic mode of existence, Dasein is aware of the finitude of its existence, but still projects forward into possibilities in the originary future. In both modes of existence the threefold structure of originary temporality remains unified.

experience of enduring. Consequently, while they remained held back or trapped within the experience of enduring, these distressing moods continued to intensify.

As mentioned previously, the threefold structure of originary temporality remained connected when the person lived in either an authentic or inauthentic mode of existence. However, the failure of the participants to live in either mode of existence created a disconnection in the unified structure of originary temporality. This disconnection in originary temporality was depicted within the participants' experience of being on hold, while they waited for a kidney transplant.

For instance, the participants' experience of uncertainty prevented them from contemplating possibilities for the future. In addition, the disruptions in lifestyle created by the dialysis treatment regime, meant they were unable to participate fully in the lifestyle they took for granted in the past. Consequently, the participants described their experience of being on hold, while they waited for a kidney transplant.

The experience of being on hold was described as being held back in a time that was separated from the narrative of their lives. The time spent on hold was not related to their past and future. Instead, it was almost completely engulfed by the relentless treatment regime of haemodialysis therapy. The moods of hopelessness and despair were palpable throughout the participants' accounts of being on hold.

These characteristics of the participants' experience of being on hold symbolised specific features of the concept of enduring, advanced by Morse (2001). As mentioned previously, Morse (2001) contended that individuals who were enduring focused on the present and this enabled them to get through the difficult situation. However, when the person predominantly focused on the present, s/he essentially blocked out the past and future. According to Morse (2001), in extreme forms, enduring disconnected the person from his/her life. These qualities of enduring seemed to correspond with the participants' experience of being on hold, while they waited for a kidney transplant.

However, as previously mentioned, Morse's (2001) concept of enduring was based on a psychological framework. Therefore, the interpretation of time embedded within the concept referred to the person's cognitive or subjective experience of time. In contrast,

the disconnection in time depicted in the participants' experience of being on hold, did not symbolise this psychological perspective of time. Rather, the interpretation of time embedded within the participants' experience of waiting for a kidney transplant was the threefold structure of originary temporality (Heidegger, 1962). Therefore, to make Morse's concept of enduring more apposite to the participants' experience of waiting, there was a requirement to replace the psychological interpretation of time entrenched within the concept, with Heidegger's (1962) description of temporality.

The integration of Heidegger's account of temporality with Morse's concept of enduring facilitated a more in-depth understanding of the disconnection in temporality illustrated in the participants' experience of being on hold. For instance, the uncertainty of waiting indefinitely for a kidney transplant meant the participants were unable to contemplate possibilities for the future. The failure to contemplate possibilities for the future implied that the originary future had lost its projective characteristics.¹²⁹ Without the projection of the originary future, the ecstatic unity of originary temporality was disconnected.

Furthermore, the restrictive treatment regime of dialysis prevented several participants from engaging fully in their normal everyday activities. This conveyed that world-time was also disrupted. Since world-time constituted the originary present, it was embedded within originary temporality. Therefore, a disruption in world-time subsequently culminated in a disruption to originary temporality.

The disconnection in originary temporality, highlighted in the participants' experience of being on hold was depicted in Morse's concept of enduring. However, by addressing the concept in terms of Heidegger's notion of originary temporality, it was possible to understand in more detail how the participants' experience of enduring the relentless wait for a kidney transplant disconnected or blocked off the past and future. Consequently, the participants remained held back in a present that was almost entirely constituted by haemodialysis therapy.

¹²⁹ See page 94 for previous discussion on the originary future.

The disconnection in ordinary temporality combined with the distressing moods, contained in the participants' accounts of being on hold, indicated that they were unable to live in either mode of existence when confronted with anxiety. These features of the participants' descriptions subsequently implied that they were unable to escape the experience of enduring while they waited for a transplant (see Figure 2, p232).

In particular, the disconnection in ordinary temporality symbolised Heidegger's (1995) description of boredom. Like anxiety, Heidegger (1995) described boredom as a fundamental existential mood.¹³⁰ There were three forms of boredom, which ranged from the most superficial to the most profound. The third form of boredom was the origin of the other two, because it disclosed the person's finite existence. Therefore, the person tried to flee or escape from the first and second forms of boredom to avoid being drawn into the third and most profound form of boredom.

As previously discussed, the participants' descriptions of waiting, described in the themes *Lost Time* and *Waiting for Kidney Transplant* epitomised the defining features of the three forms of boredom, presented by Heidegger (1995). Similarly, the features of boredom contained within the participants' accounts corresponded with specific aspects of Morse's (2001) concept of enduring. In the discussion that follows, the defining characteristics of Heidegger's (1995) analysis of boredom, contained within the participants' accounts of waiting, will be discussed in relation to Morse's concept of enduring.

In the first form of boredom, the person was forced to wait in a particular situation (Heidegger, 1995). The participants' accounts of waiting, presented in the themes *Lost Time* and *Waiting for a Kidney Transplant* indicated that they were unable to escape from the experience of waiting. Therefore, they had no option except to get through the experience of waiting. To re-iterate, enduring was described as a response, which occurred when one had no choice but to get through a difficult situation (Morse & Carter, 1995, 1996; Morse, 2001). The person focused predominantly on the present, and this focus allowed them to get through the situation. Various strategies were used to concentrate on the present, such as watching the clock, or counting (Morse, 2001).

¹³⁰ See page 158 for a more in-depth discussion on Heidegger's perspective of boredom.

The participants' accounts of living in hope while they waited for a kidney transplant highlighted their predominant focus on clock/calendar time. Embedded in their accounts was the experience of "counting down" the days, weeks, months, and years until they received a kidney transplant. Likewise their descriptions of waiting, presented in the theme *Lost Time* also illustrated their predominant concentration on clock time. For instance, in the sub theme *Killing Time*, the participants conveyed their experience of watching the clock, while they waited for the treatment to end. Similarly, their predominant focus on clock time was also emphasised in their descriptions of wasting time.

According to Heidegger (1995) when the person watched the clock, they were merely trying to gauge how long it would be until the wait was over. This was indicative of the description of enduring, advanced by Morse (2001). Morse claimed that by watching the clock and focusing on clock time, the person was merely trying to get through or endure the time until the unbearable situation was over. There were various strategies, which allowed the person to temporarily escape from enduring, such as sleeping, doing puzzles, and watching TV. The participants' accounts in the sub theme *Killing Time* signified that the time dragged, while they waited for haemodialysis to end. Consequently, they tried to kill time by performing various activities, such as reading, doing puzzles, and watching television and DVDs.

From Heidegger's (1995) perspective, time became long in the first form of boredom. Therefore, the person performed activities in an effort to pass the time and drive away the boredom. The strategies used by the participants to kill time corresponded with the first form of boredom. Moreover, these strategies indicated that the participants were enduring, while they waited for haemodialysis to end. It seemed that the strategies used to kill time were also strategies to escape from enduring.

The themes *Waiting for a Kidney Transplant* and *Lost Time* conveyed the relentless nature of the participants' experience of waiting. Because of the persistent waiting, they were unable to flee from the first form of boredom. Therefore, they progressed into the second form of boredom, described by Heidegger (1995). According to Heidegger (1995), in the second form of boredom, the person's efforts or strategies to pass the time were repressed. The participants' accounts of waiting, presented in the sub theme *Killing Time* emphasised that their efforts to kill time were suppressed during haemodialysis therapy. The suppression of the participants' efforts to kill time corresponded with the second form of boredom, described by Heidegger (1995).

As mentioned previously, Morse (2001) and Morse & Carter (1996) described various strategies used by the person to escape from enduring. These strategies were similar to the strategies used by the participants to kill time during haemodialysis therapy. It appeared that the suppression of the participants' efforts to kill time also resulted in the suppression of the strategies used to escape from enduring. Hence, this implied that the participants were unable to escape from the experience of enduring, while they waited for dialysis to end.

Because the participants' efforts to kill time were suppressed during dialysis, they essentially had nothing to do except wait for the treatment to end. Consequently, the time spent waiting during haemodialysis therapy prevented them from performing their everyday activities. Similarly, the relentless experience of waiting, described within the sub themes *Wasting Time* and *Being on Hold* prevented the participants from engaging in their normal everyday activities. This subsequently created a disruption in the characteristic features of world-time.

If we recall, world-time was the time that contained the activities performed by the person in his/ her everyday involvements in the world. It referred to the irreversible, sequence or flow of times called "nows", where the world-time present was the "now", the world-time past was the "no-longer-now", and the world-time future was the "not-yet-now". The activities performed by the person in his/her everyday involvements in the world provided world time with its irreversible sequence or flow.¹³¹ However, when

¹³¹ See page 97 for the discussion of world-time.

these activities stopped, the flowing of world-time also stopped, which brought world-time to a stand.

Heidegger (1995) emphasised that when world-time was brought to a stand, the person experienced the second form of boredom. It has already been proposed that the disruption to world-time portrayed in the participants' accounts of waiting, expressed in the sub themes *Killing Time*, *Wasting Time*, and *Being on Hold*, brought world-time to a stand.¹³² When world-time came to a stand, the “now” was not eliminated. Rather, it did not have the possibility of a transition from a “not-yet-now” (world-time future) to a “no-longer-now” (world-time past). Hence, for the duration of time that the person was unable to engage in his/her everyday activities, the present “now” was merely static. The person was forced to endure the present “now” of world-time, cut off or unbounded from the “not-yet-now” and the “no-longer-now”.

These features of the second form of boredom, which appeared in the participants' accounts of *Killing Time*, *Wasting Time*, and *Being on Hold*, symbolised Morse's (2001) concept of enduring. According to Morse (2001), the person who was enduring concentrated on the present in order to get through the unpleasant situation. Within this present-oriented state, the past and future were essentially blocked out. To re-iterate, Morse's concept of enduring primarily referred to the cognitive or subjective experience of time. Therefore, there was a need to replace this psychological interpretation of time with Heidegger's (1962) perspective of world-time in order to appropriately address the participants' experience of waiting. By expanding Morse's (2001) concept of enduring in this way, the features of the second form of boredom, which were expressed in the participants' accounts of waiting, seemed indicative of enduring.

Heidegger (1995) signified that the second form of boredom was usually transient. Once the person re-engaged in his/her everyday activities, the irreversible flow of world-time was subsequently recommenced. In other words, the standing of world-time would be overcome and the person would flee from the second form of boredom. In contrast, the participants' accounts in my study signified that their experience of waiting was

¹³² See page 158 and 198 for the previous discussion on boredom in relation to the themes *Lost Time* and *Waiting for a Kidney Transplant*.

persistent and ongoing. As a result, they were unable to flee or escape from the second form of boredom and were drawn into profound boredom.

The participants' failure to escape from the relentless experience of waiting meant they were unable to overcome the standing of world-time, which was presented in the sub themes *Killing Time*, *Wasting Time*, and *Being on Hold*. If we recall, world-time constituted the originary present and was embedded within the threefold structure of originary temporality. The person acted in world-time or the originary present based on his/her affectedness from the past, to project forward into possibilities in the future. Hence, it was the originary present or world-time that highlighted the spannedness of originary temporality, described by Heidegger (1962).

This spanned character demonstrated that originary temporality was not three separate dimensions of time. Rather, it was a unified whole, with a projective or purposeful character based on the originary future (Blattner, 1999). However, when world-time was disrupted, as a result of the participants' experience of waiting, it came to a stand. This subsequently caused the originary present to come to a stand. The participants' inability to overcome the experience of waiting meant they were unable to overcome the disruption/standing of the originary present. Consequently, the threefold structure of originary temporality was disconnected.

Furthermore, the participants' experience of being on hold signified that the uncertainty of waiting indefinitely for a kidney transplant prevented them from contemplating possibilities for the future. This conveyed that the originary future had lost its projective characteristics. Without the projection of the originary future, the ecstatic unity of originary temporality was disrupted. Therefore, this feature of the participants' experience of being on hold, while they waited for a kidney transplant, also demonstrated a disconnection in the unified structure of originary temporality.

The disconnection in the threefold structure of originary temporality created by the participants' experience of waiting, depicted the third and most profound form of boredom, described by Heidegger (1995). In the third form of boredom, originary temporality was suspended or stopped. This created a disconnection in the threefold structure of originary temporality.

Heidegger stated that the time that was suspended in profound boredom was different than our normal, everyday understanding of time, as ordinary (clock) time, or world-time (Blattner, 1999). Instead, it was the threefold structure of originary temporality, which was suspended in the third form of boredom. When originary temporality was suspended, the past and future became separated from the originary present. This meant the ecstatic unity of originary temporality was disintegrated.

The disintegration of the ecstatic unity of originary temporality forced the present ecstases to stretch and lengthen itself to fill the entire time horizon. However, without the defining features of the originary past and future, the originary present also lost its defining features. In other words, the person was not acting in the originary present, based on his/her affectedness from the past to project forward into possibilities in the future. Rather, the present was characterised by inaction and the person was compelled to endure the empty time of profound boredom.

The empty time of profound boredom was not related to the person's past and future. Therefore, while the person experienced the empty time of profound boredom, everything seemed to be without value and indifferent (Haar, 1999). The participants' accounts of waiting, contained in the sub themes *Killing Time*, *Wasting Time*, and *Being on Hold*, conveyed the empty time of profound boredom. The relentless experience of waiting meant the participants had no option but to get through the empty time of profound boredom.

Again, these features of the participants' accounts were characteristic of Morse's (2001) concept of enduring. The experience of being forced to get through an untenable situation, combined with the disconnection in originary temporality, was indicative of the concept of enduring. Morse (2001) pointed out that when enduring, the past and future were essentially blocked off, and the person was left in a present oriented state. In its most extreme form, enduring disconnected the person from life (Morse, 2001). These defining characteristics of Morse's (2001) concept of enduring were indicative of the experience of profound boredom, highlighted in the participants' experience of waiting. However, as previously mentioned, the psychological perspective of time retained in Morse's concept, meant that time was interpreted as something cognitively or

subjectively conceived by the person. Therefore, there was a requirement to replace this predominantly psychological perspective of time, with Heidegger's (1962) notion of originary temporality. By making this alteration to the concept of enduring, it was possible to provide a more fitting account of the profound boredom portrayed in the participants' experience of waiting.

From Heidegger's (1962) perspective of originary temporality, time was understood as more than just a consciously retained phenomenon. On the contrary, time as originary temporality was based on the care-structure of one's existence and was grounded in one's being-in-the-world. Thus, the disconnection in originary temporality created by boredom did not just disrupt the person's cognitive or subjective perception of time. It actually created a disruption in the person's life or existence.

Like anxiety, Heidegger (1995) described boredom as a fundamental existential mood. In other words, it illuminated the possibility of death to the individual and prompted them to live in either an authentic or inauthentic mode of existence. The accounts of several participants signified that they were unable to live in either mode of existence in response to profound boredom. Consequently, they were drawn deeper and deeper into profound boredom. As previously mentioned, the inability to live in either mode of existence produced the discomfiting moods experienced by the person on a daily basis (Heidegger, 1962, 1995).

The participants' accounts characterised the distressing moods, which accompanied their experience of waiting. For instance, the distressing moods of uneasiness, irritation, frustration, anger, and despair were described within their experience of waiting, presented in the theme *Lost Time*. Furthermore, the unpleasant moods of sadness, disappointment, depression, hopelessness, and despair were described in the theme *Waiting for a Kidney Transplant*. The ongoing nature of the participants' experience of waiting meant they were unable to flee or escape from profound boredom. Moreover, they were unable to live in either mode of existence when faced with the finitude of their existence. Therefore, the distressing moods accelerated, as the wait continued relentlessly.

According to Morse (2001), the intensification of emotions resulted in a “failure to endure” causing the person to progress into the state of emotional suffering. In contrast, the findings of my study implied that the acceleration of the distressing moods, experienced by the participants, did not result in a failure to endure. Rather, these unpleasant moods intensified because the participants “failed to escape from enduring”. The persistent nature of the participants’ experience of waiting meant they had no choice except to get through or tolerate this unpleasant experience.

As mentioned previously, Morse’s work did not address what occurred when the person was essentially trapped within the state of enduring. Indeed, Morse & Penrod (1999) highlighted the inability to address this issue, as a shortcoming in their work on suffering. Based on the findings of their study, the authors claimed that enduring might be prominent within the experience of waiting. Therefore, they recommended the need to qualitatively investigate the role of waiting, in an effort to fill this conceptual gap in their model of suffering.

It is suggested that the findings of my study went some way to addressing this conceptual gap. By combining elements of Morse’s (2001) concept of enduring with elements of Heidegger’s (1962, 1995) existential philosophy, a model was formulated to provide a more comprehensive description of the participants’ experience of waiting (see Figure 2, p232). In summary, the participants’ ongoing experience of waiting meant they were unable to escape from enduring. This culminated in the existential moods of anxiety and boredom, which highlighted the possibility of death to the participants. When confronted with this grim possibility, the participants were prompted to live in either an authentic or inauthentic mode of existence. However, the relentless nature of their experience of waiting meant they were unable to live in either mode of existence. This culminated in a disconnection in temporality and the intensification of distressing moods.

These features of the participants’ accounts depicted Morse’s (2001) concept of enduring. They implied that the participants’ failure to live in either mode of existence in response to anxiety and boredom effectively prevented them from overcoming the experience of enduring. As a result of the participants’ ongoing experience of waiting, they remained essentially stuck or trapped within enduring.

From Morse's (2001) perspective, the intensification of distressing emotions caused the person to move out of enduring into a separate state of emotional suffering. However, using Heidegger's existential perspective, we were able to recognise the acceleration of the distressing moods, contained within the participants' accounts of waiting, as an integral characteristic of enduring. The participants' ongoing inability to live in either mode of existence in response to anxiety and boredom caused their distressing moods to accelerate to the level of utter hopelessness and despair. These distressing moods were explicitly and implicitly contained in the participants' accounts of waiting. In addition, they were unable to reconnect the unified structure of originary temporality.

Alternatively, a small number of the participants described their ability to live in an inauthentic mode of existence in response to profound boredom. By choosing to live in an inauthentic mode of existence, these participants were able to alleviate the distressing moods, and reconnect the threefold structure of originary temporality, which culminated from their experience of waiting. By reconnecting the unified structure of originary temporality and developing a more positive mood, the participants' accounts suggested they had overcome the experience of enduring (see Figure 2, p232).

From Morse's (2001) perspective, the only way for the nurse to help and support the person who was enduring was through patient-centred care. However, to achieve patient-centred care, the nurse had to spend sufficient time communicating with patients, in order to recognise their specific needs (Morse, 2001). The participants' accounts contained in the theme *Communicating with the Nurses: Myth versus Reality* demonstrated that the nurses rarely spent time communicating with them when they attended haemodialysis therapy. Instead, the nurses predominantly focused on the technical and physiological aspects of patient care. It is suggested that the technologically focused context of care on the haemodialysis unit effectively hindered the provision of patient-centred care. This issue will now be discussed in further detail in the third and final section of this chapter.

5.2 THE CONTEXT OF CARE ON THE HAEMODIALYSIS UNIT

There were a number of issues within the context of care on the haemodialysis unit at the study hospital, which may have contributed to a deficit in patient-centred care. For instance, in the Republic of Ireland, the increasing number of patients requiring treatment has placed additional demands on the nurse's role in the haemodialysis unit.¹³³ The excessive number of patients requiring treatment at the study hospital resulted in the unit functioning on a 24-hour basis. Consequently, the nurses' primary responsibility was to continuously process patients through the treatment in the shortest time possible. However, this predominant focus on throughput created a barrier to effective nurse-patient communication, which was expressed by the participants.¹³⁴

It is proposed that the impetus on efficiency, which existed on the haemodialysis unit, ensured that clock or ordinary time dominated the nurses' role. However, this temporal pattern was not congruent with the threefold structure of ordinary temporality, which formed the basis of the participants' experience of waiting. Therefore, it was possible that a conflict of temporal patterns may have ensued, which contributed to the inadequate levels of communication between the nurses and the participants.

Various authors showed that a clash in temporal reference frameworks created a barrier to effective nurse-patient communication and interaction (Gibson, 1994; Young, 2002; Agich, 2003; Waterworth, 2003). According to Agich (2003), patients wanted to share their experience of illness with others, and this was the reason they sought attention from caregivers. However, if caregivers were unable to establish a common and shared perspective of time with the patient, then genuine communication was not possible. Agich (2003) contended that "care necessarily requires engagement and engagement involves people tuning into one another's temporal stream" (p145). Therefore, if the caregiver was unable to relate to the patient's temporal pattern, the service s/he provided did not have a concerned presence for the person receiving it (Agich, 2003).

¹³³ See page 7 for the number of patients with ESRD on dialysis in Ireland.

¹³⁴ See page 205 for the participants' accounts of communicating with nurses.

It is suggested, that because of the conflict in temporal patterns, the nurses' communication with the participants did not have a concerned presence. Indeed, the participants' accounts highlighted that the degree of nurse-patient communication rarely progressed beyond the level of superficial dialogue.¹³⁵ The deficit in meaningful communication meant the participants' experience of waiting, described in the themes *Lost Time* and *Waiting for a Kidney Transplant* was neither recognised nor addressed by the nurses on the haemodialysis unit. Instead, they primarily concentrated on the technical and physical aspects of care.

According to Perry, Roberts & Kelly (2004), the technological orientation of many healthcare professionals working in the area of dialysis therapy reflected an "acute" model of patient care delivery. Within this model, patients had minimal input into their care and relied on the healthcare professionals to "cure" their illness (Perry, Roberts & Kelly, 2004).

Based on the findings of my study, it seemed that the context of care on the haemodialysis unit might also have epitomised this acute model of care delivery. Indeed, this was illustrated within the participants' accounts of waiting for a kidney transplant because they seemed to interpret ESRD to be an acute rather than a chronic illness. The participants viewed ESRD as a temporary problem, which would be fully alleviated with a kidney transplant. By receiving a kidney transplant, the participants understood that they would return to a normal life free of ESRD and dialysis therapy. Consequently, from the participants' perspective, a kidney transplant was deemed synonymous with "recovery" or "cure".

In particular, the information the participants received from the healthcare team about the average waiting time for a kidney transplant encouraged this inaccurate perspective of illness.¹³⁶ Most of the participants received this numerical information at the time of their diagnosis with ESRD. However, they misunderstood the information to mean that they would receive a kidney transplant in a relatively short duration of time. Hence, this contributed to the participants' belief that ESRD and dialysis was a temporary setback.

¹³⁵ For example, see the accounts of Nancy (p209), Ali (p206), Elena (p208-209), Danny (p207-208).

¹³⁶ See page 173 and 178 for the participants' accounts of living in hope, and uncertainty while they waited for a transplant.

Thorne et al (2006) signified that when healthcare providers incorporated a numerical claim in their prognostic information, it was retained more sharply by the patient than the contextual information about the illness. The authors conducted a large qualitative study ($n = 200$) to explore the patient's perspective of the meaning of numerical information in cancer communication. For many participants, statistical information allowed them to cope with the uncertainties of their illness, manage their emotional distress, and find a basis for hope. However, there were also disparities between the healthcare professionals' understanding of statistical probabilities, and the participants' interpretations of this numerical information. In particular, this created distress for the participants when their experience was less positive than that suggested by the statistical probabilities (Thorne et al., 2006).

Like the participants in the study by Thorne et al, the participants in my study also reported the uncertainty and distress they experienced when they passed their expected date for a transplant.¹³⁷ As mentioned previously, the nurses on the haemodialysis unit were the primary care giver for these participants. However, the nurses' predominant orientation toward the technical and physiological aspects of care meant they did not recognise or respond to the participants' needs for ongoing information and support. Therefore, the participants' inaccurate perspective of ESRD, as an acute or short-term problem was not corrected.

According to Charmaz (1991), perceptions of acute illness frequently influenced healthcare providers' assumptions about chronic illness. Moreover, the author suggested that patients with a chronic illness tended to adopt the same perspective of illness as portrayed by healthcare professionals. Therefore, many chronically ill patients adopted the assumptions, expectations, and time perspectives of those with an acute rather than a chronic illness.

¹³⁷ See page 178 for the participants' accounts of uncertainty, while waiting for a transplant.

By failing to address the participants' misapprehensions about kidney transplantation, it is proposed that the nurses on the haemodialysis unit essentially reinforced a perspective of ESRD as an acute illness, specifically acute renal failure (ARF). Regrettably, this acute perspective is disappointingly inadequate in the care of patients with ESRD. In ARF, the illness trajectory occurs as a linear series of stages, which progresses from diagnosis with ARF, to an established treatment plan, to recovery. In recovery, the person's renal function returns, allowing him/her to resume a normal life.

Unlike ARF, the course of ESRD is cyclical in its progression. The patient progresses from a diagnosis with ESRD, to dialysis therapy, to kidney transplantation (if there are no contraindications), and eventually the patient returns to dialysis when the kidney transplant fails. Therefore, kidney transplantation is merely a treatment and not a cure for ESRD. There is no recovery in the course of ESRD, just a series of treatments to manage the physiological symptoms of the chronic, progressive disease.

According to Kierans (2005), new medical technologies have been revolutionary in their ability to maintain and extend life. However, these technologies have moulded the person's experience of illness and healing by performing medical interventions and procedures "around a linear drive towards progress and outcome" (p345). This has culminated in a perspective of kidney transplantation as an "end game" or final point in the trajectory of ESRD (Kierans, 2005; p345).

By failing to address the participants' misperceptions about the chronic nature of their illness, it is suggested the nurses on the haemodialysis unit at the study hospital were reinforcing the perspective of transplantation as the end of ESRD. They subsequently ignored the participants' needs for ongoing information and support throughout the illness trajectory. As a result, the participants adapted the belief that ESRD and haemodialysis therapy was a short-term problem. They had no idea about the realities of chronic illness and subsequently remained hopeful of recovery with a transplant.

According to Oliffe et al (2007), the absence of effective communication resulted in healthcare professionals making assumptions about the patients' information needs. These assumptions were related to the concept of autonomy. The authors implied that healthcare professionals in Western society, tended to associate the notion of autonomy

with individual freedom and self-determination. From this perspective, the person was deemed ultimately responsible for his/her actions and decisions.

By adapting this Western ideal of autonomy, Oliffe et al (2007) emphasised that healthcare professionals made various assumptions about the information needs of their patients. Firstly, these clinicians assumed that the responsibility for seeking information and making decisions, rested solely with the individual. Thus, if the patient required information, s/he was ultimately responsible for signifying this need. Secondly, they assumed that the responsibility for misinterpretations and misunderstandings in information were also placed with the patient (Oliffe et al., 2007).

The absence of effective nurse-patient communication, highlighted by the participants in my study, may have occurred because the nurses adapted the Western ideal of autonomy, advanced by Oliffe et al (2007). These nurses did not provide the necessary follow-up information and support required by the participants. They also placed the responsibility for seeking out information entirely with the participants. Consequently, the participants' misapprehensions about the average waiting time for a kidney transplant were not rectified.

A qualitative study by Wellard (1992) highlighted how the dilemmas faced by nurses ($n=8$) employed in dialysis units in Australia, affected their communication with patients. The nurses reported situations where the medical team had not incorporated their nursing expertise in treatment decisions regarding patient care. In particular, the nurses were excluded from decisions regarding the acceptance of patients onto the dialysis programme, and the selection of patients for transplantation.

The nurses indicated that the medical team provided superficial information to patients about the chronic nature of their condition. As a result, the patients were ill informed about the consequences of life with ESRD and dialysis therapy. This created a dilemma for the nurses, because the patients would eventually seek confirmation and clarification of the information they had received from the medical team. However, the nurses felt powerless to disclose information that was different to that provided by the doctors. They were concerned that they might diminish the trust that existed between the patient and the doctors if they contradicted the medical advice.

It seemed that the dilemma articulated by Wellard (1992) might have contributed to the absence of nurse-patient communication, reported by the participants in my study. Based on the numerical information the participants had received from the medical team at the time of their diagnosis with ESRD, they believed they would receive a kidney transplant quite quickly. This allowed the participants to remain hopeful of recovery. Consequently, if the nurses addressed these misconceptions, they would have contradicted the medical team, and potentially destroyed the participants' hope.

From Thorne et al's (2006) perspective, ongoing dialogue was required to inform patients about the significance of numerical information, and to sustain realistic hope. The authors emphasised the need for a positive relationship between the patient and the healthcare professional to ensure this ongoing communication with patients. However, if we recall, the participants' accounts in my study highlighted how the lack of nurse-patient communication, subsequently prevented the development of a positive nurse-patient relationship.¹³⁸

Thorne & Robinson (1989) found three distinct stages in the patient-healthcare provider relationship: the naive trust stage, the disenchantment stage, and the guarded alliance stage.¹³⁹ As the chronic illness progressed, the patient's relationship with the healthcare provider also progressed until it reached the guarded alliance stage. Thorne (2006) emphasised that it was imperative for healthcare professionals to recognise these stages as a necessary and natural process. This allowed them to deal with the difficulties that arose in the early stages of their relationship with patients. It also allowed healthcare providers to adapt their approach to communication, to ensure it was more conducive to the progression of a long-term relationship with the patient. From Thorne's (2006) perspective, it was primarily the healthcare professionals' responsibility to recognise and manage the communication tensions that arose in their interactions with the patient.

The participants in my study repeatedly attended haemodialysis therapy three times each week. Based on the repetitive and ongoing nature of the treatment, it seemed reasonable to suggest that the nurses should have been able to recognise and respond to

¹³⁸ See page 205 for the participant's accounts of communicating with nurses.

¹³⁹ See page 220-221 for the previous discussion on the work of Thorne & Robinson (1989).

communication tensions within their interactions with patients. However, the participants' accounts implied that the nurses did not address these communication tensions. Hence, the nurse-patient relationship did not progress beyond the disenchantment stage, presented by Thorne & Robinson (1989).¹⁴⁰

The authors pointed out, that the disenchantment stage culminated in feelings of dissatisfaction and animosity amongst patients. The participants' descriptions of communicating with the nurses signified that they were dissatisfied with the nurses' level of engagement. Indeed, the distressing moods of disappointment, frustration, hostility, and anger were embedded within their accounts.

Thorne (2006) insisted that the willingness of healthcare professionals to communicate effectively, ensured the patient's "shattered cure expectations" were addressed (p8). Moreover, the patient was facilitated and supported to embark on the journey of chronic illness. However, where communication tensions went unresolved, a struggle for control often ensued with regard to who was ultimately in charge of managing the illness. A frequent manifestation of this tension involved the patient failing to comply with their prescribed treatment (Thorne, 2006). If we recall, the failure of the nurses to communicate openly with David resulted in his refusal to comply with the prescribed treatment regime.¹⁴¹

Like Thorne & Robinson (1989), a qualitative study by Morse (1991) provided a model for understanding the relationships negotiated between the nurse and the patient. There were four types of mutual relationship, which developed from a superficial clinical type, to a more involved type, which the nurse and patient mutually agreed upon over time (Morse, 1991).

The "clinical" relationship occurred when the patient was being treated for a minor issue. The length of time the nurse and patient spent together was brief, with the nurse simply making an assessment and applying a treatment. The nurse-patient interaction was superficial. It involved the nurse making statements such as "How are you today?"

¹⁴⁰ See page 221 for the discussion on the disenchantment stage of the nurse-patient relationship in relation to the participants' accounts.

¹⁴¹ See page 210 for David's account.

Nice day out". This superficial level of involvement was deemed satisfactory by the patient because s/he had no expectation of the nurse beyond the care required (Morse, 1991).

The "therapeutic" relationship was also of short duration, and the patient's needs were not extensive. The nurse provided the care quickly and effectively, as the treatments provided were not serious or life threatening. The nurse met the patient's psychosocial needs, which usually included the provision of routine reassurance prior to minor procedures. In both the clinical and therapeutic relationship, the nurse viewed the patient, first as a patient, and second as a person (Morse, 1991).

Conversely, in the "connected" and the "over-involved" relationships, the nurse viewed the patient, first as a person, and second as a patient. For instance, in the connected relationship, the patient and the nurse had been together for a long time. Therefore, the relationship had evolved beyond a clinical and a therapeutic level. The extreme needs of the patient particularly accelerated this process. In this relationship, the patient decided to trust the nurse, and the nurse decided to meet the patient's needs. The nurse acted as the patient's advocate, mediating on behalf of the patient with family and medical staff (Morse, 1991).

An over-involved relationship occurred when the patient and the nurse had spent an extensive length of time together, and had developed mutual respect, trust, and care for each other. It also occurred when the patient had extraordinary needs and the nurse chose to meet them. The nurse was so committed to the patient, that at times s/he overlooked the treatment regime, the physician, the institution, and her responsibilities toward other patients. The nurse was a complete confidant of the patient and was treated as a member of the patient's family. Therefore, the patient relinquished the patient role, and the nurse relinquished the professional relationship (Morse, 1991).

Drawing on the findings of Morse (1991), it seemed reasonable to suggest that the relationship between the nurse and participants on the haemodialysis unit should have developed to the level of the connected type. The long-term nature of the interaction, combined with the patients' needs, demanded this level of nurse-patient relationship. Morse (1991) considered the over-involved relationship as dysfunctional because the

nurse tended to ignore the needs of other patients, staff, and the institution. Nonetheless, the sheer length of time that the nurses spent with the patients on haemodialysis therapy, and the excessive needs of some of these patients implied that the nurse-patient relationship could potentially have progressed to the over-involved type.

In contrast, the participants' accounts of communicating with nurses illustrated that the nurse-patient relationship seemed to be at the level of clinical relationship. The nurse merely performed a physical assessment of the patient prior to the treatment (e.g. calculated weight gain, measured blood pressure, reviewed blood levels) and applied the dialysis treatment. The interaction between the nurse and the patient was superficial and consisted of minimal personal involvement.¹⁴² However, unlike the clinical relationship, the participants in my study were dissatisfied with the level of interaction they had with the nurses. They had expectations of the nurse beyond the care requested and received. They also clearly required more personal involvement from the nurses. These findings indicated that the nurse-patient relationship was not mutual but rather unilateral.

From Morse's (1991) perspective, involvement and interaction required mutual connection between the nurse and patient. However, when one person decided not to develop a connected relationship with the other, a mutual relationship was not achieved. In unilateral relationships, one person was unwilling or unable to develop the relationship to the level desired by the other. Therefore, the relationship did not represent mutual commitment, and was considered unilateral (Morse, 1991).

Based on the participants' accounts of communicating with the nurses, it is suggested the nurses were either unwilling or unable to develop the relationship to the desired level of the participants. Hence, the relationship between the nurse and the participants on haemodialysis therapy was unilateral. As mentioned previously, the sheer length of time the nurses spent with the patients each week implied that the nurse-patient relationship should have evolved to the level of the connected type. However, the participants' accounts clearly illustrated that this was not the case. Instead, it seemed that the nurses were using strategies to inhibit their interactions with patients, which subsequently hindered the development of a positive nurse-patient relationship.

¹⁴² For example, see the account of Nancy (p209), Ali (p206), Elena (p208-209), Danny (p207-208).

According to Morse (1991), nurses tended to use blocking strategies if they were not committed to the patient as a person, or were “burnt out” and did not have the energy to invest in the relationship. There were various strategies described by Morse (1991), which inhibited the development of a connected relationship. For instance, the author described the deliberate depersonalisation of the patient as an inhibiting strategy. It involved the nurse refusing to talk or chat to the patient, and avoiding eye contact. Another strategy involved the nurse maintaining an efficient attitude, which gave the patient the impression of busyness. This allowed the nurse to focus on physical tasks and avoid the more humanistic elements of care, such as providing counsel and information to patients (Morse, 1991).

These strategies used by the nurse to decrease involvement in the nurse-patient relationship were expressed within the participants’ descriptions of communicating with the nurses.¹⁴³ For example, the participants indicated that the nurses on the haemodialysis unit appeared to be excessively busy all the time. They rarely spoke to them during haemodialysis therapy, and predominantly focused their attention on the technical and physical elements of care. This narrow scope of practice meant the participants’ concerns and need for information about their illness and treatment were not acknowledged or addressed.

As mentioned previously, the nurses’ assessment of the patient prior to, and during each dialysis treatment was also structured around the technical and physical elements of care. It is proposed that this narrow approach to assessment may also have served as a blocking strategy, which limited the development of a connected nurse-patient relationship.

A study by Bryans (2000) highlighted how the nurse’s approach to the assessment of a patient effectively encouraged or hindered the development of a collaborative nurse-patient relationship. The author identified two approaches to patient assessment within the context of community nursing: (1) the patient-focused approach, and (2) the nurse-

¹⁴³ See page 205 for the participants’ descriptions of communicating with the nurses.

agenda-led approach. Each approach generated various behaviours in both the nurse and the patient.

The patient-focused approach to assessment was collaborative and involved a reciprocal and conversational style. Both parties had some control over events and the nurse acknowledged the patient's concerns, questions, needs, and feelings. Therefore, advice and information given to the patient by the nurse was patient-specific rather than generalised. The nurse tailored her information to the patient's needs and/or specific context of the visit. The patient responded positively to this assessment approach, and to the suggestions, advice, and information of the nurse. The patient also initiated topics, asked questions, and freely volunteered information (Bryans, 2000).

The superficial level of nurse-patient communication, which occurred in my study, meant the nurses' approach to the assessment of the participants was not at a patient-focused or collaborative level. Instead, it seemed that the nurses structured their assessment of patients specifically around the physical and technical aspects of haemodialysis therapy. By using this narrow approach to the assessment of patients, the nurses essentially failed to attend to the individual concerns and needs of the participants. Therefore, it seemed that the nurses' approach to the assessment of patients depicted the nurse-agenda-led approach, described by Bryans (2000).

Within the nurse-agenda-led approach, the assessment was rigidly structured by a 'nurse question-patient response' strategy (Bryans, 2000). Thus, the topics deemed important to the nurse dominated, while the patient-initiated topics and concerns were constrained. The nurse did not acknowledge the patient's feelings, and even interrupted patient statements and responses in order to adhere rigidly to the nurse's agenda. Advice and information given to the patient by the nurse was impersonal and generalised, rather than patient-centred. This approach to assessment created conflict between the nurse and patient. For example, the patients stopped offering cues and information, and only answered the specific questions asked by the nurse. In addition, the patients responded negatively to the nurse's advice and suggestions, by either rejecting suggestions, asserting their own competence, or giving neutral responses.

These negative responses were also expressed in the participants' accounts of communicating with the nurses during haemodialysis therapy. They conveyed their dissatisfaction with the shallow level of the nurse-patient relationship. Hence, beneath their accounts was the desire for a more involved relationship with the nurses on the haemodialysis unit. Morse (1991) stated that if patients required more than a unilateral relationship with nurses, they might resort to coercive or manipulative behaviours. These behaviours included offering gifts or bribes, cajoling, nagging, and demanding. The patient used these behaviours to entice the nurse to become more involved and to ensure nursing care and attention was received (Morse, 1991).

These coercive behaviours were depicted in the narratives of David and Chris.¹⁴⁴ For instance, David's narrative conveyed the hostility and anger he felt towards some nurses for failing to recognise his needs and concerns. As a result of his experience of being ignored by these nurses, David simply "demanded" that the nurses provide the care and treatment he required. Similarly, it appeared that Chris's continuous "nagging" of the nurses might have been a way to coerce them into engaging with him during his treatment. Even when the nurses tried to ignore him, he indirectly got their attention by creating arguments with other patients.

Unfortunately, many of the strategies used by patients to coerce or manipulate nurses into engagement, had the opposite effect and actually increased the distance between the nurse and patient (Morse, 1991). Indeed, this was demonstrated in the follow-up interview with Chris. Because of his coercive behaviours, the nurses had labelled him a disruptive patient, and subsequently isolated him on the haemodialysis unit.

Other authors referred to the potentially negative outcomes of the nurse's use of blocking strategies in their involvement with patients. For instance, Rowe (2003) indicated that some nurses responded to the person's suffering, by avoiding his/her suffering altogether. They achieved this avoidance by concentrating on their tasks and by viewing their work with patients as "just a job". Similarly, a qualitative study by Hobson (2002) found that nurses deliberately used distancing strategies, to allow them to detach from the overwhelming suffering of patients. The study explored the ethical

¹⁴⁴ See page 210-211 for the accounts of David and Chris.

decision making of nurses working with cancer patients. From Hobson's (2002) perspective, the acute model of care delivery on the cancer unit at the study hospital, specifically prevented the nurses from acknowledging dying as a significant issue for patients.

The ward was designated an acute treatment unit, yet the nurses were caring for patients with cancer. This created a clash between "acute" and "chronic/palliative" cultures of care. While care of the dying was a large proportion of the nurses' work, the acute model of care on the unit was so strongly pro treatment, that the provision of palliative care was neither encouraged nor supported. This was highlighted in the communication patterns of the nurses, because they avoided talking about death and dying, either amongst themselves or with patients (Hobson, 2002). Instead, the nurses concentrated on the completion of tasks in an effort to avoid engaging in deeper existential discussions with patients. From Hobson's perspective, this task-oriented approach to care, acted as a distancing strategy, which allowed the nurses to emotionally detach from the overwhelming suffering of the patients.

If we recall, the findings of my study signified how the moods of anxiety and boredom, which culminated from the participants' experience of waiting, confronted them with the possibility of imminent death. Furthermore, the persistent nature of their experience of waiting meant they were unable to overcome these existential moods. Consequently, they were continuously faced with the grim reality of death.

However, like the findings of the study by Hobson, the nurses on the haemodialysis unit failed to communicate beyond a superficial level with the participants in my study. Therefore, these nurses did not engage in discussions with the participants about their prognosis or existential issues. Rather they focused specifically on the completion of the physical and technical acts of care. These findings seemed to suggest that the nurses on the haemodialysis unit were using distancing strategies, in order to avoid engagement in existential discussions with patients. However, by avoiding this depth of dialogue, the participants retained unrealistic views of their illness as a temporary problem, which would be solved with a transplant.

Davison & Simpson (2006) emphasised that the avoidance by healthcare professionals to enter discussions about prognosis and end of life issues, resulted in patients with ESRD having unrealistic expectations about their treatment. The study explored hope and advance care planning in nineteen patients with ESRD. A qualitative, in-depth approach was employed incorporating open-ended interviews and inductive qualitative data analysis. The researchers did not provide a connection to any methodological or philosophical framework in the study. The findings indicated that many healthcare professionals believed that end of life discussions destroyed the patient's hope, and interfered with the development of a trusting patient-healthcare provider relationship.

In contrast to these views, the participants in the study described the process of advance care planning, as a means of enhancing hope. These participants indicated how the provision of information and support by healthcare professionals early in the illness trajectory, had a positive effect on their experience of ESRD. This information empowered the participants, prepared them for the long-term impact of the illness, and enhanced their relationship with staff and significant others. The authors concluded that while advance care planning may identify new concerns for the patient, it did not destroy hope. Instead, advance care planning provided an opportunity for people to reformulate their hope, making it more realistic with their future (Davison & Simpson, 2006).

The participants in the study by Davison & Simpson (2006) expected healthcare professionals to initiate discussions about advance care planning and end of life issues. They did not feel that it was their responsibility to ask or seek out this information and support. However, the failure of healthcare professionals to initiate advance care planning discussions meant that some participants were ill prepared for their future with chronic illness. This created potential barriers to hope.

The findings of my study showed how the lack of communication between the nurses and the participants created a barrier to discussions about prognosis, advanced care, and end of life issues. Therefore, the nurses did not respond to the existential concerns generated by the participants' experience of waiting. It is suggested that the use of distancing strategies by the nurses on the haemodialysis unit meant the participants' existential concerns were not addressed. Therefore, this contributed to the

intensification of distressing moods, and the disconnection in ordinary temporality, endured by the participants.

Drawing on the work of Iris Murdoch, Scott (2006) emphasised that as human beings, we responded to each situation by either pushing ourselves to grow, or by protecting ourselves from distress. However, by repeatedly protecting ourselves from challenge and distress, we developed a self-protective wall, or shell around ourselves, which led to the desiccation of one as a human being (Scott, 2006). From Scott's perspective, such self-protection in nurses ultimately resulted in emotional and psychological withdrawal from the patient. This withdrawal from the patient subsequently dulled, suppressed, or even prevented the development of moral sensitivity within the nurse (Scott, 2006). The study by Hobson (2002) depicted this loss of moral sensitivity in the nurses' accounts. The author claimed that when the distancing process in the nurse-patient relationship became more entrenched, the nurses became less motivated to act on their moral instincts. As a result, they experienced an "eroded sense of moral agency".

Various authors have elucidated the moral dimensions of nursing practice (Griffin, 1980, 1983; Scott, 1995; Niven & Scott, 2003; Scott, 2006). Niven & Scott (2003) specifically highlighted "respect for persons" as a fundamental moral value required in the caring practices between healthcare professionals and patients. Drawing on the work of Carson (1995), the authors called for a more extensive interpretation of the current principle of "respect for persons" to be incorporated into the care of patients.

Carson (1995) declared that the principle of respect in healthcare was largely understood from the perspective of biomedical ethics. From this viewpoint, respect meant respect for the autonomy and self-determination of the individual. Carson (1995) claimed that this narrow viewpoint of respect served as a reminder "to mind our own business [and] leave each other alone" (p105). However, this was not appropriate in the care of the person who was chronically ill or disabled. Rather, the adherence to this interpretation of respect merely culminated in this patient group being abandoned and left alone to deal with their illness (Carson, 1995).

Carson (1995) appealed for the extension of our interpretation of the principle of respect. He based his appeal on the premise that people who were chronically ill required more than just respect. They needed the healthcare provider to recognise the person behind the illness. However, from Carson's perspective, many healthcare providers overlooked the human significance of the person's experience, and instead concentrated on the medical/physiological facts of the case. Consequently, there was a need to broaden the care of the chronically ill to include not only the principle of respect, but also the principle of regard (Carson, 1995).

Carson (1995) claimed that healthcare providers needed to have due regard for the recipients of their care. His notion of regard implied that healthcare providers should communicate effectively with patients. They needed to be attentive and considerate, and engage in conversation that went beyond the level of superficial familiarity. More importantly, the notion of due regard referred to a way of being with the patient, where the healthcare provider was able to recognise and affirm the patient as a person, with a unique experience. This unique experience subsequently formed the basis of the patient's care. The participants' narratives in my study illustrated that the nurses on the haemodialysis unit did not engage in acceptable levels of interaction and communication with patients. As a result, it is suggested that the nurses were unable to express due regard for these patients.

In a more recent publication, Scott (2006) indicated that in order for healthcare professionals to provide morally sensitive care, they needed to attend to more than just the physical elements of patient care. This broader sensitivity called on healthcare professionals to recognise the patient, as a fellow human being with unique and specific needs. As mentioned previously in the literature review, Scott (2006) contended that illness was influenced by a range of background or contextual factors, such as the patient's lifestyle, future, family, and loved ones. The author emphasised that these factors must be recognised and acknowledged by healthcare professionals, to ensure that patient care was morally sensitive and person-centred (Scott, 2006).

The participants in my study emphasised an urgent need for morally sensitive and patient centred care, which gave due regard to their unique experience of ESRD and dialysis. They desired and expected a level of nursing care that extended beyond the mere completion of technical and physical tasks. However, the lack of nurse-patient communication meant the nurses failed to recognise the important contextual and background factors, which formed the basis of the participants' experience of illness. Instead, they concentrated primarily on the physical and technical elements of patient care.

It is suggested that the nurses on the haemodialysis unit at the study hospital need to develop their role to ensure the provision of morally sensitive and patient-centred care. However, to achieve this objective, there is a requirement to alter the technologically focused approach to patient care, which currently exists on the haemodialysis unit.

5.2.1 CONCLUDING COMMENTS

This chapter provided an overall discussion of the findings in relation to the existing literature. The findings illustrated that the experience of waiting was significant for the participants in the study. In particular, the participants' experience of waiting culminated in the existential moods of anxiety and boredom, presented by Heidegger (1962, 1995). These moods highlighted the threefold structure of originary temporality to the participants, which confronted them with the possibility of death. When faced with the possibility of death, the participants were pressed to live in either an authentic or inauthentic mode of existence.¹⁴⁵ However, the participants' relentless experience of waiting meant they were unable to live in either mode of existence. The inability to live in either mode of existence culminated in a range of distressing moods, and a disruption in the threefold structure of originary temporality.

¹⁴⁵ In the inauthentic mode of existence, Dasein absorbs itself in everyday activities to avoid reflecting on its death and finitude. In the authentic mode of existence, Dasein is aware of the finitude of its existence, but still projects forward into possibilities in the originary future. In both modes of existence the threefold structure of originary temporality remains unified.

The unpleasant moods, and the disruption in ordinary temporality, which characterised the participants' experience of waiting, epitomised certain features of the concept of enduring, advanced by Morse (2001). However, the psychological perspective retained within this concept had to be supplemented with the existential philosophy of Heidegger to make it more characteristic of the participants' experience. Therefore, a new "model of enduring" was developed, which combined specific features of Morse's concept of enduring with Heidegger's (1962, 1995) existential interpretation of mood and temporality.

According to Morse (2001), in order to assist and support the person who was enduring, nursing care had to be patient-centred. The nurse must take time to interact and communicate with patients, in an effort to recognise and respond to their unique care needs. In contrast, the findings of my study signified that the nurses on the haemodialysis unit spent very little time communicating with the participants. As a result, the nurses failed to recognise or address the participants' relentless experience of waiting. Moreover, the participants' experience of enduring was subsequently overlooked. Instead, the technologically focused context of care on the haemodialysis unit meant the nurses concentrated almost entirely on the technical and physiological acts of care.

These findings emphasised the need to alter the current context of care on the haemodialysis unit in an effort to foster a more person-centred approach to care.¹⁴⁶ The next chapter addresses this issue and recommends an alternative approach to the care of patients on the haemodialysis unit at the study hospital.

¹⁴⁶ The use of the term 'person' in person-centred approach to care refers to 'Dasein', the temporally situated human being who is constituted by his/her past, present, and future.

CHAPTER 6 : RECOMMENDATIONS, LIMITATIONS AND CONCLUSION

This chapter discusses the recommendations of the study for nursing and healthcare. Recommendations based on comparatively small-scale studies should always be cautious, and this approach will be adapted within the recommendations section of this thesis. Also, in the spirit of hermeneutical dialogue, recommendations are not “orders” but suggestions and proposals that invite further discussion, dialogue, proposals, critique, and clinical innovation. The recommendations of the study are followed by a discussion on the limitations of the study, and the overall conclusion to the study.

The participants’ accounts in my study highlighted the predominantly technological context of care, which existed on the haemodialysis unit at the study hospital.¹⁴⁷ This approach to care created a barrier to effective communication, which hindered the provision of ongoing information and support to patients. It is proposed that there is a need to change the culture and context of care on the haemodialysis unit at the study hospital to overcome this narrow scope of practice. Therefore, a progression toward a model of supportive care for patients on the haemodialysis unit is proposed as one way to achieve this objective. It is suggested that this shift in paradigms of care might enable healthcare professionals to acknowledge and attend to the person’s unique experience of illness and treatment.

In the following discussion, the concept of supportive care for patients with a progressive, chronic illness, such as ESRD will be addressed. The participants’ experiences of ESRD and haemodialysis therapy, presented in my study, will be used to highlight the potential benefits of supportive care within this patient group. This will be followed by a discussion on the use of a continuous quality improvement (CQI) framework to implement the elements of supportive care on the haemodialysis unit at the study hospital.

¹⁴⁷ See page 205 for the theme “*Communicating with Nurses: Myth versus Reality*” for examples of this technical/physiological focus of care.

6.1 TOWARD THE SUPPORTIVE CARE OF THE HAEMODIALYSIS PATIENT

The World Health Organisation (2004) European Report on Palliative Care identifies that people with a progressive chronic illness might benefit from palliative care services. The report emphasises that most research on palliative care seems to have focused on people living with cancer. However, it continues to point out that there is growing evidence that patients with progressive, chronic illness have similar concerns, and sometimes, greater needs than those experiencing cancer.

While the literature illustrates that renal patients have a shortened life expectancy, and experience a high symptom burden (Saini et al., 2006; Brown, Chambers & Eggeling, 2007), the involvement of palliative care teams are rarely included in the care of these patients throughout the illness trajectory. Instead, palliative care is limited to patients who decide to refuse, or withdraw from dialysis therapy.

This narrow view of palliative care is emphasised in the unpublished National Renal Strategy Review (2006). This review indicates that patients in the Republic of Ireland who decide not to avail of dialysis therapy for ESRD “should continue under the care of the renal unit, with continued conservative management. As events evolve, there may be a need for palliative care services for such patients” (p33).

Some authors indicate that the term palliative care contributes to the reluctance of healthcare professionals to incorporate these services into the care of patients with a chronic illness (Main et al., 2006; Noble et al., 2007). In particular, it seems the associations the term has with imminent death, makes it difficult for healthcare professionals to broach with the chronically ill (Main et al., 2006; Noble et al., 2007). Therefore, the use of the term “supportive care” has evolved in an effort to incorporate the principles and practice of palliative care into the care of patients with renal disease. It appears that the term supportive care is more readily accepted by healthcare professionals, since it suggests an approach to care directed towards helping patients and carers to manage the illness (Main et al., 2006; Noble et al., 2007).

Reiter & Chambers (2004) have published a textbook, which specifically sets out various issues involved in the supportive care of the renal patient. The authors describe supportive care, as an approach that incorporates both restorative care and palliative care. Restorative care refers to the application of the disease-specific treatment, such as dialysis. Palliative care refers to any additional treatment, which alleviates unpleasant symptoms, but is not deemed to be curative. It includes all types of medical, nursing, and psychosocial care, used to enhance the quality of life of the patient (Reiter & Chambers, 2004).

The authors emphasise that “patients should not have to have a terminal illness, or be in the terminal phase of an illness, to benefit from excellent pain and symptom management or to have psychosocial issues addressed” (p18). Other authors subscribe to this view, insisting that through supportive care, disease control and quality of life can be maximised for patients at all stages of renal disease (Levy, Chambers & Brown, 2004; Reiter & Chambers, 2004; Noble et al., 2007).

It is recommended that by adapting this supportive approach to care on the haemodialysis unit at the study hospital, the shortcomings of the current technologically focused approach to care delivery might potentially be reduced. By providing renal supportive care to the patients, the restorative functions would overlap seamlessly with the palliative care functions, ensuring the holistic care of the patient. In other words, the application of the technical treatment of haemodialysis therapy would occur simultaneously with effective patient-centred care.

There were four overarching components of supportive care for the renal patient identified in the existing literature: holistic care throughout all stages of the illness trajectory; an interdisciplinary approach to care; open and honest communication; and the support of family and carers. Based on the findings of my study, it is recommended that two additional components need to be added to this list to ensure the supportive care of the patients on haemodialysis at the study hospital. These include: a structured approach to the allocation of dialysis spaces, and a patient-friendly treatment environment. Each of the six components of supportive care will now be addressed in relation to the findings of my study.

6.1.1 HOLISTIC CARE THROUGHOUT ALL STAGES OF THE ILLNESS TRAJECTORY

According to Noble et al (2007), the goal of supportive care for the renal patient is to provide holistic care from diagnosis to death. However, healthcare professionals tend to focus more specifically on the scientific and technical characteristics of renal disease (Perry, Roberts & Kelly, 2004; Noble et al., 2007). As a result, the need for supportive care throughout the illness trajectory is poorly recognised.

The participants in my study emphasised how the technical and physiological focus of patient care created a barrier to effective communication. The superficial level of nurse-patient communication and interaction meant the participants did not receive the necessary levels of support and information to enable them to come to terms with their illness and treatment. Therefore, it is suggested that a holistic approach to patient care is required, to help overcome this narrow scope of practice.

6.1.2 AN INTERDISCIPLINARY APPROACH TO CARE

Supportive care requires an interdisciplinary team approach (Levy, Chambers & Brown, 2004; Reiter & Chambers, 2004; Noble et al., 2007). While ESRD is a life-limiting illness, the focus of supportive care both acknowledges and responds to how patients can live their lives to the optimum, with social and psychological support from the interdisciplinary team as required (Chambers, Germain & Brown, 2004).

According to Reiter & Chambers (2004), the nephrology team usually address medical, psychosocial, and existential problems associated with renal disease and dialysis treatment. However, within the supportive care model, healthcare professionals are educated in palliative care philosophies (Reiter & Chambers, 2004; Noble et al., 2007). By interpreting supportive care from this interdisciplinary perspective, there is scope for collaboration with a multitude of excellent services. Based on the work of various authors, an extensive list of these services has been drawn up, which include palliative care nurses and physicians, pain specialists, rehabilitation specialists, physiotherapists, psychologists, renal counsellors, social workers, complementary therapists, and clergy (Ahmedzai & Walsh, 2000; Reiter & Chambers, 2004; Noble et al., 2007).

The aim is to complement the management of the patients' illness and treatment by providing exceptional symptom control and reinforcing their psychosocial and spiritual support (Levy, Chambers & Brown, 2004). As the disease progresses and complications accumulate, smooth referral to a hospice or palliative care service is possible due to the existing holistic approach to patient care (Noble et al., 2007). This avoids the unfortunate situation where healthcare professionals fail to recognise dying, until it is too late for the patient and family to benefit from a palliative care approach.

The need for an interdisciplinary approach to care, calls for a change in the context of the renal unit, which in previous times has been self-contained (Noble et al., 2007). While the renal literature emphasises the need for a multidisciplinary approach to care, supportive care requires an interdisciplinary approach, which extends beyond the renal team (Noble et al., 2007).

During the process of conducting this study, it was identified that the haemodialysis unit at the study hospital had not yet achieved an effective multidisciplinary approach to care. The unpublished National Renal Strategy Review (2006) verifies that multidisciplinary team staffing varies greatly between renal services throughout Ireland. Within the unit at the study hospital, there is one member of staff assigned to take on the role of social worker, counsellor, and anaemia coordinator for patients from the pre-dialysis stage throughout all stages of the illness trajectory. It seems reasonable to suggest, that despite the nurse's best efforts, it was not possible for one person to perform these roles effectively. More importantly, it clearly highlighted the significance awarded to the psychosocial aspects of patient care on the haemodialysis unit at the study hospital.

Based on the participants' accounts, there seemed to be inadequate levels of collaboration between the nurses and the medical team caring for the patients. The nurses on the dialysis unit seemed to be excluded from medical decisions about the selection of patients for dialysis and kidney transplantation. They had no input into the medical information the participants received about their diagnosis and kidney transplantation. Consequently, from the information received from the medical team, several participants understood that haemodialysis was a temporary setback, alleviated by a transplant.

The lack of collaboration between the nurses and the medical team caring for these patients meant this issue was not addressed. Instead, the nurses seemed to restrict their communication with patients to a superficial level, to avoid engaging in discussions about the realities of ESRD.

There also appeared to be insufficient collaboration between healthcare professionals on the haemodialysis unit, and the Department of Organ Procurement and Transplantation in Ireland. As mentioned previously, this department stipulates that the Body Mass Index (BMI) of the person must to be below 32 before s/he was considered for transplantation. Yet, two participants in my study described being sent for pre-transplant assessments, despite being well above this BMI level.

If close collaboration between healthcare professionals on the haemodialysis unit and the transplant unit occurred, these patients should have been provided with this information. In addition, they should have been commenced on a weight loss programme before they ever attended the transplant unit. Unfortunately, the absence of active collaboration between both units means these strategies are not in place. Therefore, the participants experienced the disappointment of making wasted journey(s) to the transplant department merely to be told they were too overweight to be considered for transplantation.

These findings illustrate that there are limitations in the multidisciplinary approach to patient care on the haemodialysis unit, which need to be addressed. After this deficit is addressed, it would be beneficial to progress towards the level of interdisciplinary collaboration required for renal supportive care.

6.1.3 OPEN AND HONEST COMMUNICATION

Noble at al (2007) identified effective and clear communication as an attribute of renal supportive care. Open and honest communication is imperative from diagnosis throughout all stages of the illness trajectory (Levy, Chambers & Brown, 2004; Reiter & Chambers, 2004; Noble et al., 2007). This ensures that the provision of care focuses on the desires and goals of the person (Reiter & Chambers, 2004). Open communication

facilitates the process of shared decision-making between healthcare professionals, the patient, and family/carers (Levy, Chambers & Brown, 2004; Reiter & Chambers, 2004).

As the findings of my study indicated, there was a lack of open communication between the nurses and the participants.¹⁴⁸ The nurses were the primary healthcare providers for the patients while they were on haemodialysis therapy. Therefore, they had the most opportunities to interact and communicate with these patients. However, it seemed that the technologically focused context of care on the haemodialysis unit effectively prevented open and honest nurse-patient communication.¹⁴⁹

The participants' accounts highlighted how the lack of communication with nurses on the haemodialysis unit hindered the continuity of patient care. The absence of clear communication procedures between patients, nurses, and the multidisciplinary team resulted in patient care that was fragmented and uncoordinated. Instead of emphasising patients' needs, it seemed the nurses' attention was placed specifically on the technological and physical features of the haemodialysis treatment.

The absence of appropriate levels of communication meant the nurses did not discuss the extent of the participants' prognosis and treatment. They essentially overlooked the participants' experience of relentless waiting, described in the themes *Lost Time* and *Waiting for a Kidney Transplant*. Moreover, they failed to attend to the participants' ongoing needs for information and support to enable them to come to terms with the long-term and progressive characteristics of their illness.

Supportive care of the renal patient requires open dialogue about advance care planning, and depending on the stage of the illness, the patient's preferred place of death (Cohen et al., 2001; Holley, 2004). Reiter & Chambers (2004) contend that "while the only certainty is that all people will die, and therefore should engage in advance care planning, the reality of a limited life expectancy is present for patients with ESRD" (p21).

¹⁴⁸ See page 205 for the participants' accounts of communicating with the nurses.

¹⁴⁹ See page 245 for the discussion on the context of care in the haemodialysis unit.

According to Holley (2004), advance care planning is a process of supportive care that occurs throughout the course of ESRD. It involves forward planning for supportive care i.e. planning for the restorative and palliative care needs of the patient throughout the course of the illness. It also allows patients the opportunity to achieve control over their care, strengthen relationships with those close to them, and prepare for death (Holley, 2004).

The findings of my study showed how the participants' experience of waiting culminated in the existential moods of anxiety and boredom. These moods confronted the participants with the possibility of imminent death. Indeed, the persistent nature of their experience of waiting meant they were unable to overcome these moods. Thus, the participants were continuously faced with the close proximity of death.

As mentioned previously, the shallow communication between the nurses and the participants created a barrier to discussions about prognosis and end of life issues. Therefore, the nurses did not respond to the participants' existential concerns. Perhaps if the nurses had intervened, they may have been able to assist the participants to overcome the distressing moods of anxiety and boredom. Instead, by overlooking these issues, the nurses were not providing patient centred care.¹⁵⁰ More importantly, they were failing to recognise and respond to the participants' need for counselling and supportive care. This might signify why the critical need for a qualified counsellor on the haemodialysis unit was not recognised.

It is suggested that a patient support group might also provide a channel of communication, which would contribute to renal supportive care. This service is currently not provided for patients on the haemodialysis unit. A support group would allow common concerns and experiences to be identified and shared amongst patients. The mutual support received from this type of group might serve to reinforce to patients that they are not alone on the journey through chronic illness.

¹⁵⁰ For example, see the accounts of Danny (p207-208), Nancy (p209), David and Chris (p210-211).

Based on the findings of the study, it is suggested that the open and honest communication, which is integral to supportive care, would be extremely beneficial within the care of the patients on haemodialysis at the study hospital.

6.1.4 THE SUPPORT OF FAMILY AND CARERS

The support of family and carers is essential in renal supportive care situations (Levy, Chambers & Brown, 2004; Reiter & Chambers, 2004; Noble et al., 2007). The people caring for patients with ESRD are confronted with a number of concerns, including the demands of the treatment regime on their lives, the loss of income incurred if the patient is unable to work, and ultimately the fear of losing their loved one (Noble et al., 2007). Moreover, the family and carers witness the patient's response to his/her illness and treatment including the unpleasant physiological symptoms and distressing moods. Since families also live through the trauma of renal disease with the patient, they also require support (Noble et al., 2007).

The findings of my study implied that there was a deficiency in person-centred care. Therefore, the need to involve family and carers within decisions about the patients' care was subsequently lacking. The participants' accounts illustrated that the threefold structure of ordinary temporality formed the basis of their experience of ESRD and haemodialysis therapy. In other words, their past, and future formed an essential part of their current experience of illness and treatment.

As previously mentioned, the past contains the significant set of relationships we have because of being born into a particular situation. This means that relationships with family and carers are an integral feature of the patient's past. As such, these relationships must be incorporated into decisions about the patient's care. However, it seemed that the technologically focused approach to care delivery adapted on the haemodialysis unit meant the nurses essentially overlooked the vital role of the patient's family and carers. Indeed, throughout my time interviewing patients on the haemodialysis unit, I never encountered a family member attending a dialysis session with a patient.

According to Noble et al (2007), the financial pressures in many hospitals means the support of family and carers is often lacking. Instead, the tendency is to focus on the needs of the patient. Based on the findings of my study, it is suggested that the current context of patient care on the haemodialysis unit resulted in healthcare professionals failing to pay due regard to the participants' needs. In turn, this culminated in a failure to recognise the important role of the family and carers in the participants' care. Therefore, the need for renal supportive care with its emphasis on the support of family and carers is a priority on the haemodialysis unit at the study hospital.

6.1.5 A STRUCTURED APPROACH TO THE ALLOCATION OF DIALYSIS SPACES

The participants' accounts highlighted that they wasted a substantial amount of time waiting for haemodialysis machines to become available. This prevented them from engaging in many of their everyday activities, which created unnecessary distress. In particular, the absence of a well-organised and structured approach to the allocation of haemodialysis spaces on the unit was responsible for the participants' delays.

It seemed that if dialysis machines were available, nurses allocated patients to these machines, even if they arrived outside of their allocated dialysis time. However, this technical focus of care created major upheaval and upset for the patients who arrived at their allocated time, and were left waiting needlessly for a space to become available.

It is recommended that a well-organised and structured approach to the allocation of dialysis spaces on the haemodialysis unit be developed and maintained. By planning the allocation of dialysis spaces more effectively, and adhering to this plan, the nurses would potentially contribute to the supportive care of the patients.

Once a structured approach to the allocation of dialysis spaces is drawn up, there is also a need to develop a structured timetable for the hospital taxi service. This timetable would inform taxi drivers of the time they are required to collect patients. Some participants' accounts indicated that they were forced to wait excessive amounts of time because taxi drivers arrived either too early or late to take them to and from their treatment. The hospital taxi service is simply a local taxi company that has an account with the hospital. The hospital pays substantial sums of money for taxis for patients on

haemodialysis therapy. Therefore, the hospital should try to ensure that the service is meeting the needs of the patients.

6.1.6 A PATIENT-FRIENDLY TREATMENT ENVIRONMENT

The participants' accounts of killing time emphasised that the treatment environment of the haemodialysis unit was not patient-focused. Therefore, they had nothing to do during treatment except wait for the treatment to end.

The only potential diversions available for the patients on the haemodialysis unit were televisions, and conversation with fellow patients and nurses. However, the televisions had to be shared amongst patients, which meant the participants could rarely choose what they wanted to watch during haemodialysis therapy. In addition, the headphones occasionally did not work, which limited the possibility of using television as a way to kill time.

There was a haemodialysis machine placed between patients during treatment, which created a barrier to communication. Furthermore, patients were rotated to alternate dialysis spaces each time they attended for treatment. Consequently, they found it difficult to develop a rapport with other patients. As mentioned previously, there was very little communication between the nurses and participants. The absence of nurse-patient communication meant the participants were unable to use conversation with nurses as a way to pass the time during dialysis therapy.

These findings demonstrated that there was essentially nothing provided in the treatment environment to make the patients' time during haemodialysis more pleasant, comfortable, or entertaining. Instead, it seemed that the treatment environment reflected the perspective of the nurses working there, and as such was entirely established around the technical and physiological aspects of patient care.

As mentioned previously, the superficial level of nurse-patient communication meant the nurses did not recognise or respond to the participants' experience of killing time during haemodialysis therapy. It seemed the nurses did not recognise the participants' need for a more patient-friendly treatment environment.

6.2 USING CONTINUOUS QUALITY IMPROVEMENT TO IMPLEMENT THE ELEMENTS OF SUPPORTIVE CARE

It is anticipated that the elements of supportive care will be introduced using a continuous quality improvement (CQI) framework. Many healthcare organisations have used a continuous quality improvement (CQI) framework to ensure the highest quality of care is delivered to patients (Arya & Callaly, 2005). CQI is a change management tool, which allows healthcare teams to re-design whole systems of care through small changes (Knight, 2007).

CQI takes a 'bottom-up' approach, which means that quality improvement is encouraged at all levels. This avoids the 'top-down' approach, which involves the introduction of a quality framework that is led by managers and imposed on the service. This strategy is often seen as inappropriate to healthcare practitioners and will subsequently be unsupported (Arya & Callaly, 2005). Commitment from the healthcare team is essential from the beginning to ensure that CQI becomes part of everyday practice.

In order to gain the commitment of the healthcare team to the process of CQI, it will first be necessary to highlight the need for changes in practice. This will initially involve the dissemination of the findings of my study to practitioners on the haemodialysis unit. Dissemination of the findings will occur through formal meetings with the consultants on the haemodialysis unit, and both formal and informal meetings with the nursing management and staff. It is anticipated that scheduled presentations of the findings will also be organised and provided for all practitioners working on the haemodialysis unit.

These meetings/presentations will serve to inform practitioners about the key findings of the research. However, it is suggested that in order for healthcare practitioners to recognise the need for change through CQI, it will be necessary to encourage them to reflect on current practice. It is anticipated that this will be achieved through clinical supervision. Clinical supervision provides a structure for reflective practice and acts as a

catalyst for practice development (Rolfe, Freshwater & Jasper, 2001). Although reflection can be undertaken alone, the process of guided reflection through clinical supervision enables the practitioner to expand his/her personal interpretations to incorporate other perspectives (Rolfe, Freshwater & Jasper, 2001).

A study by Kilcullen (2007) highlighted that clinical supervision was a new concept in nursing in the Republic of Ireland. The study explored the experiences of clinical supervision for nurses involved in an MSc/Graduate Diploma programme in renal and urological nursing at Dublin City University. Qualitative interviews were conducted with both supervisors ($n=5$) and supervisees ($n=5$). The findings indicated that both groups viewed clinical supervision as a positive approach to enhance professional development in nursing through reflection.

I was one of the clinical supervisors who participated in this study and emphasised the beneficial effects of clinical supervision in facilitating positive change in nursing practice. I also participated with other colleagues at Dublin City University to provide workshops to prepare healthcare practitioners to take on the role of clinical supervisor for this programme. Therefore, it is anticipated that I would initially take on the role of clinical supervisor at the study hospital to assist practitioners to reflect on their practice. However, as the healthcare team begin to take ownership of the CQI process, I would provide workshops to enable these practitioners to take on this role.

Due to a lack of time and resources, it is anticipated that the practitioners on the haemodialysis unit may be unable to engage in individual supervision sessions. Rolfe, Freshwater & Jasper (2001) emphasise that when individual supervision sessions are not practically feasible, group clinical supervision sessions should be employed. Therefore, it is my intention to have group supervision sessions with staff on the haemodialysis unit to facilitate reflection. I intend to draw on my past experience and skills developed while supervising renal and urological nurses. I will also incorporate the information and advice provided by Rolfe, Freshwater & Jasper (2001; p108-126) on how to plan, organise, and competently facilitate a clinical supervision group.

The objective of the clinical supervision sessions will be to allow healthcare practitioners to discuss their thoughts, feelings, and actions in everyday practice. This process will enable the practitioners' personal beliefs, assumptions, and knowledge to be illuminated. Heidegger's existential-phenomenological concepts will provide a framework for clinical supervision sessions with healthcare practitioners. Jones (1998) has highlighted the beneficial contribution of Heidegger's existential-phenomenological perspective within clinical supervision in palliative care nursing. According to Jones (1998), anxiety, the finitude of existence, and the certainty of death are issues that health professionals are confronted with repeatedly. This is why a method of clinical supervision based on Heidegger's work is so appropriate for these professionals (Jones, 1998).

It is anticipated that the existential-phenomenological approach of Heidegger will offer a useful framework for enabling healthcare practitioners on the haemodialysis unit to reflect on themselves as temporal and finite beings. The narratives of the participants gleaned from my study will be used as a basis to enable practitioners to identify the distress caused by the experience of waiting. The narratives will also be used to provoke practitioners to recognise that the person's current experience of illness is based on his/her past and future. Since death is part of the person's future, practitioners will be encouraged to recognise the existential concerns of patients with ESRD on haemodialysis therapy. As the clinical supervision sessions progress, the existential moods of anxiety and boredom will be introduced to discussions, along with the model of enduring, developed within this study.

According to Rolfe, Freshwater & Jasper (2001), an essential part of the clinical supervisor's role is to facilitate practitioners to reflect on how this new knowledge and understanding can lead to actions in the practice setting. Based on the new knowledge and understanding developed within the clinical supervision sessions, the practitioners will be facilitated to recognise the technologically focused context of care that exists on the haemodialysis unit. They will also be facilitated to identify the potential shortcomings of this context of care and the need to implement the elements of supportive care within the unit. This will involve discussions around the six elements of supportive care already addressed earlier in this section.

Patient involvement is also a central element of CQI, as services must be re-designed according to their needs, choices, and experiences (Knight, 2007). Therefore, the aim is to disseminate the findings of this study to all patients on the haemodialysis unit. I will spend time on the haemodialysis unit discussing the findings of the study with patients. In addition, a summary of the findings will be developed into a patient-friendly leaflet and will be given to all patients on the haemodialysis unit. This leaflet will include my contact details and will advise patients who would like further information to contact me.

As mentioned previously, a patient support group is not currently available for patients on the haemodialysis unit at the study hospital. It is anticipated that a support group would be organised for patients, families, and carers. This group would provide a forum to disseminate the findings of my study. The narratives of the participants would be used to provide topics for discussion amongst members of the support group. It is hoped that these narratives would facilitate conversation amongst patients, families, and carers and allow their common concerns and experiences to be identified and discussed.

By sharing experiences with other patients, the members of the support group would realise they are not alone with their illness. The support group would also provide a forum for sharing information amongst members. The discussion of experiences, thoughts, feelings, and moods within the group would provide the peer support that is desperately needed by the patients on haemodialysis at the study hospital.

It is intended that the planning, organisation, and facilitation of this support group would be undertaken with the assistance of the Irish Kidney Association (IKA). The IKA was formed in 1978, by patients for patients and their families. The Association provides help and support to newly diagnosed renal failure patients and to patients who are already receiving renal replacement therapies. One of the aims of the IKA is to disseminate information about kidney disease to patients and their families. It is important to reiterate that many patients travel long distances to get to the dialysis unit at the study hospital. Therefore, organising the support group near the dialysis unit would make it difficult for these patients to attend. However, there are currently twenty-five branches of the IKA in the Republic of Ireland. Therefore, through collaboration

with the Association, I would be able to target branches that are near the areas where the patients live. This would enhance the patients' ability to attend the group(s) and ensure the findings of the study were disseminated widely.

The IKA publishes 'Support', a quarterly newsletter that is posted free to each patient with renal failure. The Association has requested a report on the overall findings of my study with the intention of publishing it in this newsletter. This newsletter would be an excellent medium to inform patients, families, and carers about the findings of the study. It would also provide a way to advertise the support groups. The Association also provides free patient manuals and informative booklets relating to renal disease and renal replacement therapy. Therefore, I intend to seek their advice and assistance in the development of a patient information leaflet highlighting the findings of my study.

6.2.1 THE QUALITY CYCLE

Once the need for change is emphasised and the practitioners and patients are aware that the process of change will commence, there is a need to begin the 'quality cycle'. The concept of the 'quality cycle' is a fundamental component of CQI, and consists of repeated successions of the 'plan, do, study, act' (PDSA) cycles (Langley et al, 1996). In the 'plan' stage, an objective is set and a plan to achieve the objective is developed. In the 'do' stage of the quality cycle, the plan is carried out. During the 'study' stage, the outcomes of the quality cycle are studied or analysed and a summary of what was learned is developed. In the 'act' stage of the framework, decisions are made about the subsequent changes required for CQI. It will only be feasible to move onto the next stage (i.e. plan stage) if there is sufficient support for the need to implement change.

Ayra & Callaly (2005) recommend that a lead person should be selected and assisted to develop a team of enthusiasts to initiate and support the CQI framework. It is suggested that a lead person from the medical team and the nursing team on the haemodialysis unit at the study hospital will be selected to achieve this objective. It is proposed that in the long-term, the aim is to change the technological context of care on the haemodialysis unit to the supportive care approach discussed earlier. It is acknowledged that some of the elements of supportive care will take a substantial amount of time to implement. However, the 'plan, do, study, act' (PDSA) cycles of CQI relies on small-scale changes,

which are informed by feedback. This cyclical approach means that change proceeds on a relentless basis, eventually influencing organisational culture (Arya & Callaly, 2005).

It is anticipated that there are small-scale changes that could be planned and implemented immediately on the haemodialysis unit. For instance, the need to communicate and interact with patients on an ongoing basis should be emphasised by the lead nurse as a high priority objective on the haemodialysis unit. In particular, the need to provide patients with open and honest information about their illness and treatment is urgently required. Patients need to be provided with realistic information about kidney transplantation. They need to know what the waiting process for a transplant involves and should be supported to get on with their lives while they wait. They also need information and support from nursing and medical staff on an ongoing basis to enable them to manage the long-term and progressive nature of their illness and treatment. For some patients in the advanced stages of illness, this should incorporate discussions about prognosis and end of life issues.

There is an urgent requirement for active collaboration between the members of the multidisciplinary team. In particular, this includes the nurses, medical team, and the practitioners at the transplant centre. An active level of collaboration is essential to ensure all practitioners provide the same information and advice to patients. Otherwise, patients receive different messages and misinterpret the information received. If collaboration and communication between members of the multidisciplinary team were enhanced, there would be less risk of patients becoming increasingly distressed. It would also help to overcome the fragmented and uncoordinated approach to care described by the participants in this study.

It is also anticipated that the service managers on the renal unit could facilitate rapid changes, which would improve the quality of patient care. As mentioned previously, the renal nurse specialist on the haemodialysis unit held a recognised qualification in counselling. However, the numerous other tasks, which were part of her role as nurse specialist, meant she never had enough time to spend counselling patients. The hospital did not seem to have difficulties recruiting nurses to work on the haemodialysis unit. Therefore, if a senior nurse on the haemodialysis unit were transferred into the role of

renal nurse specialist, this would allow the renal nurse specialist to move into the role of counsellor.

By having a full-time counsellor on the haemodialysis unit, the patients' concerns would be identified and managed more proactively. In collaboration with the nursing staff on the haemodialysis unit, the counsellor would provide the psychosocial support the person needs to navigate their way through their illness. The use of counselling therapies would facilitate patients to overcome the distressing moods and emotions culminating from their illness. Moreover, if patients required help engaging in daily activities or returning to work, they could be assisted with these goals. In this way, the counsellor could act as the lead person for the patients within the CQI framework, summarising their key concerns and difficulties in an effort to inform the change process.

There are other changes, which could be implemented immediately and would enhance the quality of patient care on the haemodialysis unit. For instance, the designated lead nurse should collaborate with the nurses on the unit to develop a structured timetable for the allocation of dialysis machines. All nurses should agree to adhere to this timetable to avoid patients having to wait unnecessarily for machines. Similarly, a structured timetable should be drawn up for the taxi drivers to inform them of the exact times they have to collect patients. It should be made clear that the hospital will not pay for fares if the patients are not collected on time. Nurses should also strive to ensure that patients who travel together in a hospital taxi start and finish dialysis at the same time. This would also help patients to overcome the experience of waiting needlessly after dialysis therapy.

There are also immediate changes, which would make the treatment environment more patient-friendly. The dialysis machines should be re-arranged to ensure they are not blocking patients from engaging in conversation. Likewise, by communicating and interacting with patients during dialysis, the nurses would assist the patients to pass the time during treatment. Moreover, they would be able to identify the shared interests of specific patients and have them situated near each other during treatment. As this study illustrated, the participants with ESRD on haemodialysis therapy were confronted with unique and complex problems. These problems are often best understood by patients

with the same illness and treatment. Therefore, placing patients with similar experiences beside each other during dialysis therapy would enhance peer support and interaction between patients.

Family, friends, and carers should be encouraged to accompany patients to dialysis if possible. This would provide a useful way for the patient to leisurely pass the time during treatment. It would also allow healthcare practitioners to interact with these people and provide support, which is an element of supportive care.

On a more long-term basis, other developments should be introduced including the provision of individual televisions at each dialysis station with fully functioning headsets and a high quality sound system. Internet access should be made available for patients who would like to work, or play computer games on laptops during treatment. Portable DVD players should also be made available, so that patients could watch movies as a way to pass the time. It would be ideal to offer a range of complementary therapies for patients during haemodialysis therapy, such as relaxation therapy, aromatherapy, reflexology, and music therapy. Exercise therapy is also provided for patients during haemodialysis therapy in some hospitals in Europe and the USA and would provide a beneficial and healthy way to pass the time for patients.

The Irish Kidney Association might be willing to fund the introduction of some of these services on the haemodialysis unit. The Punchestown Kidney Research Fund has also raised substantial funds since 1990 to support research projects that improve the life of patients with kidney disease. The funds have been used to sponsor an Art Therapy Programme for dialysis patients in two dialysis centres in the Republic of Ireland. Through funding from the Punchestown Kidney Research Fund, it is hoped that some of the services outlined above would be introduced to the dialysis unit at the study hospital. It is also hoped that the possibility of creating an Art Therapy Programme would be considered.

It is anticipated that an interdisciplinary approach to patient care would be gradually implemented on the haemodialysis unit. It seemed that the technological context of care on the dialysis unit meant the need for an interdisciplinary approach to patient care was not recognised. Because of this technological context of care, practitioners on the

haemodialysis unit simply overlooked the chronic nature of ESRD and dialysis. Consequently, the physical and psychosocial concerns experienced by patients regarding the long-term outcomes of their illness and treatment were not addressed.

It is important to point out that many of the interdisciplinary professionals required to provide supportive care for the renal patient are already available at the study hospital e.g. psychologists, social workers, physiotherapists, pain specialists, occupational therapists, palliative care physicians and nurses, and clergy. Therefore, it would simply involve a designated member of the CQI team on the haemodialysis unit communicating and collaborating with these professionals to ensure their services are extended to include patients on the haemodialysis unit. By incorporating a collaborative interdisciplinary approach, the healthcare practitioners on the haemodialysis unit could work together with these professionals to ensure the holistic needs of the patients are met.

6.2.2 EVALUATION OF THE CONTINUOUS QUALITY IMPROVEMENT PROCESS

The evaluation and analysis of outcomes are a core component of the quality cycle of CQI and occur during the ‘study’ stage of the PDSA cycle. The absence of evaluation can allow people to assume that their practice does not need to change. Therefore, continuous monitoring assists the service to recognise problems and deficits and ensures that these gaps are addressed leading to improvement in the entire system (Ayra & Callely, 2005; Knight, 2007). It is anticipated that the evaluation of the quality cycles will be performed using various research approaches. There is a need to produce feedback information from patients to staff, which will inform staff of the areas of care that have improved and areas that need further improvement.

A study by Hyrkäs & Lehti (2003) reported on the use of systematic patient feedback as a way to evaluate a continuous quality improvement process on three hospital wards. The researchers developed a questionnaire to evaluate patients’ satisfaction with healthcare. They based the questionnaire on previous work related to patient satisfaction surveys. The questionnaire was piloted and improved before inclusion in the study. The

findings indicated that systematic patient feedback during the CQI process improved the quality of care on the ward.

With some minor additions, the questionnaire developed by Hyrkäs & Lehti (2003) would be appropriate to assess patients' satisfaction with care on the haemodialysis unit at the study hospital. The following broad issues were included in the questionnaire (1) overall satisfaction with care (2) satisfaction with treatment, (3) adequacy of information, (4) guidance and patient counselling, (5) consideration for patients' opinions and wishes, (6) staff competence, (7) assistance in addressing the patient's current health problem, (8) staff collaboration, and (9) satisfaction with the layout/environment of the ward/unit. In addition to these questions, the following two questions would also be included (10) satisfaction with the hospital transport service (11) satisfaction with the waiting time for a dialysis machine to become available. The question (i.e. question 9) that assesses satisfaction with the layout/environment of the ward/unit would address the patient's satisfaction with the diversionary activities provided on the unit.

The primary aim of using this questionnaire is to produce information for staff, which would serve to evaluate the implementation of immediate changes in practice during the quality cycles of the CQI process. It is anticipated that these questionnaires would be administered monthly to patients. There is a full-time research nurse on the renal unit at the study hospital that would be available to participate in this task. The feedback from these questionnaires would be reported to managerial staff and to practitioners attending the group clinical supervision sessions. It is hoped that this feedback would act as a catalyst for continuous improvement in practice.

The hermeneutic phenomenological approach used in my study was a suitable approach to identify patients' experiences of their illness and treatment. Therefore, it is recommended that research to evaluate the CQI process should incorporate this methodology to develop an in-depth account of the positive and negative experiences of the patients at the study hospital. In particular, the insights gained from the follow-up interviews with the participants in my study suggest that it would be worthwhile to follow the person's experience over time. The existing research related to the person's experience of ESRD has not employed longitudinal studies. Therefore, a

phenomenological methodology incorporating a longitudinal approach would allow the changes in the participants' experience to be documented over time. A longitudinal approach would also allow the outcomes of the quality cycles to be evaluated on an ongoing basis.

It is recommended that the findings of this hermeneutical study would also serve to evaluate the robustness of the "model of enduring" developed within this study. This would allow the model of enduring to be developed and refined over time. The development of the model would allow its applicability to be assessed within other groups of renal patients (peritoneal dialysis and kidney transplant patients) and within patients with other chronic illnesses.

There is also a need to evaluate the outcomes of the CQI process using an observational study. In particular, there is a need to analyse the daily activities of practitioners in their care of patients on the haemodialysis unit. A study of this nature would serve to evaluate whether the planned objectives of the quality cycles were being achieved. Various researchers have used observational studies to assess nursing activities and have provided interesting insights into why nurses do not engage in direct patient care activities, such as communication and interaction.

For instance, an observational survey of the activities of nurses by Jinks & Hope (2000) suggested that the majority of activities performed by nurses did not involve direct contact with patients. The researchers conducted over sixty hours of observations with ten registered nurses of various grades on an acute surgical ward at a District General Hospital (DGH) and a Community Hospital (CH) in Wales. The findings demonstrated high numbers of activities related to the management and co-ordination of care and high frequencies of indirect care. Jinks & Hope (2000) indicated that these findings represented the 'glue function' of nursing, described by McCloskey et al (1996). The 'glue function' referred to the coordinating function of the nurses' role. Instead of being involved in direct patient care, nurses were viewed as the co-ordinators of care. In other words, the nurses maintained the holistic overview of care given by all members of the healthcare team, rather than be caregivers to patients.

Oliver & Refern (1991) explored the interpersonal communication between nurses and elderly patients using patient-focused observations of nurse-patient interactions. Five elderly patients were observed individually over two days for each patient. The findings indicated that out of a total 137 nurse-patient interactions, 99 (72%) were concerned with the physical aspects of care. The findings also indicated that very little expressive touch took place between nurses and patients. Expressive touch is a non-verbal form of communication, which conveys a person's feelings, personality, and attitudes to the other person. Out of the 726 touches given, 23% were expressive while the remainder were instrumental touches i.e. touch that occurs during physical acts of care.

It is anticipated that the use of observational studies, such as the ones outlined above would be useful to evaluate whether the elements of supportive care are being implemented. The findings of these studies would also identify further changes, which need to be made within the CQI process. These findings would be discussed during group clinical supervision sessions to facilitate practitioners to reflect on what they have learned during the quality cycles and decide what further changes need to be implemented. It is expected that the clinical supervision sessions would enable practitioners to identify their own training and education needs to ensure they are able to actively contribute to the CQI process. Thus, the PDSA quality cycle would continue on an ongoing basis. Through the continuous cycles of CQI, it is hoped that over time a model of supportive care could be implemented and developed on the haemodialysis unit at the study hospital, which is evolutionary and meets the needs of patients.

6.3 LIMITATIONS OF THE STUDY

The sample size, and the qualitative methodology employed in this study, preclude broad generalisation of the findings to the larger population of patients on haemodialysis therapy. Nonetheless, the findings of the study yielded rich, in-depth information about the participants' experience of ESRD and haemodialysis therapy.

As mentioned previously, the participants requested to be interviewed during haemodialysis therapy. However, there may have been some limitations with conducting interviews in the treatment environment. While measures were taken to reduce the noise during interviews, the dialysis machine alarms meant this was not

always possible. Overall, this noise did not appear to affect the flow of conversation during interviews.

Privacy was maintained as much as possible during the interviews. However, collecting data during haemodialysis therapy may have prevented disclosure in some participants. Thus, their ability to openly discuss their experience of the illness and treatment may have been inhibited. Alternatively, responses may have been given in a socially acceptable manner to avoid potentially negative impacts on their care.

The lengthy dialysis process often creates tiredness and fatigue. These complications may have potentially impeded the participants' ability to respond and recall experiences during the interviews.

Because of the potential limitations outlined above, it is suggested that it would be beneficial to conduct interviews with participants in a more suitable environment. Indeed, I conducted the follow-up interviews with two participants in their own homes. These participants had received kidney transplants and were no longer attending the haemodialysis unit. The privacy and reduced noise levels meant these interviews were more relaxed, and free flowing. It seemed that being in the comfort and privacy of their own homes, enabled the participants to disclose their experiences in a more open manner. In future studies, I would try to conduct interviews in the patient's home or in an environment, which was more comfortable, quiet, and private.

This research specifically used qualitative interviews as a data collection technique. The use of other data collection methods, such as group interviews, observations, and personal journals may have enhanced the richness of the data. Finally, additional follow-up interviews over time would also have potentially enhanced the depth and richness of the data, and provided more contextual information about the participants' experience of ESRD and haemodialysis.

6.4 CONCLUSION TO THE STUDY

This study provided a detailed, in-depth, and accurate description of the experiences of ESRD for sixteen participants on hospital-based haemodialysis therapy in Ireland. The experience of waiting was developed as a constitutive or overarching pattern within the study. This pattern consisted of three themes: *Lost Time*; *Waiting for a Kidney Transplant*, and *Communicating with Nurses: Myth versus Reality*.

The experience of waiting had not previously been identified as a significant feature in the existing research related to the person's experience of ESRD. Therefore, it is anticipated that the findings of this study will supplement and contribute to the existing body of literature on this topic. This is important, because the more informed healthcare practitioners are about patients' experiences of ESRD, the better equipped they will be to provide care that meets their specific needs.

In particular, the Heideggerian phenomenological methodology employed in the study allowed this alternative perspective of the person's experience of ESRD to be illuminated. While other studies have used this methodology to explore the person's experience of ESRD (Rittman et al., 1993; Sloan, 1996; Sloan, 2002), these studies did not emphasise Heidegger's perspective of time or temporality. In contrast, Heidegger's (1962) philosophical analysis of time specifically formed the basis of my study into the person's experience of ESRD and haemodialysis therapy. Indeed, it is proposed that the temporal characteristics of Heidegger's philosophy facilitated the participants' experience of waiting, to be identified as a constitutive pattern within the study.

To re-iterate, the participants' experience of waiting, illustrated in the themes *Lost Time* and *Waiting for a Kidney Transplant*, culminated in the existential moods of anxiety and boredom, presented by Heidegger (1962, 1995). According to Heidegger (1962, 1995), these existential moods highlighted the possibility of death to the person and prompted them to live in either an authentic or inauthentic mode of existence. The relentless experience of waiting meant the participants were unable to live in either mode of existence. This culminated in the intensification of distressing moods, and the disruption of ordinary temporality.

The existing literature highlighted the lifestyle disruptions created by the “time-consuming” nature of haemodialysis therapy (Nagle, 1998; Hagren et al., 2001; Heiwe, Clyne & Dahlgren, 2003; Hagren et al., 2005). However, in contrast to this literature, it was not linear or clock time that was significant in the participants’ experience of waiting, described in my study. Instead it was the threefold structure of originary temporality, portrayed by Heidegger (1962) that formed the basis of the participants’ experience of waiting.

In addition, the existential interpretation of anxiety and boredom, which culminated from the participants’ experience of waiting, was also dramatically different to the psychological interpretation of these concepts, presented in the existing literature. This literature described anxiety and boredom as distressing psychological, emotional, and cognitive responses occurring within the individual. While anxiety was discussed as a prevalent response in the person with ESRD, boredom was not identified as a significant factor within this literature. However, a review of the literature specifically related to boredom, highlighted that the concept was also primarily interpreted as a psychological or cognitive response (Hill & Perkins, 1985; Perkins & Hill, 1985; Farmer & Sundberg, 1986; Vodanovich & Kass, 1990; Vodanovich, 2003; Lee & Mittelstaedt, 2004).

The alternative perspective of anxiety and boredom as existential moods presented in this thesis will contribute to our knowledge and awareness of these moods. It is anticipated that this new knowledge will assist nurses and other healthcare practitioners to recognise anxiety and boredom, and respond more appropriately to the person’s experience of these moods.

In particular, certain features of the concept of “enduring”, formulated by Morse (2001) also encapsulated the intensification of the unpleasant moods and the disconnection in temporality, depicted in the participants’ experience of waiting. However, Morse’s concept of enduring was specifically based on a psychological or cognitive perspective of emotion and time. Therefore, there was a need to substitute this psychological perspective with Heidegger’s existential account of mood and temporality, in order to incorporate the participants’ experience of waiting. Based on this merger, a new “model of enduring” was proposed, which comprehensively described the participants’

experience of waiting, presented in the study. The Model of Enduring proposed within this thesis would provide a useful framework for understanding and recognising the experience of waiting, illustrated by the participants.

Morse (2001) claimed that nurses needed to communicate and interact regularly with patients in order to recognise and respond to their experience of enduring. However, the participants' accounts in my study signified that the nurses on the haemodialysis unit spent very little time communicating with them during their treatment. The participants' experience of communicating with the nurses was discussed in the third and final theme in the study, titled *Communicating with Nurses: Myth versus Reality*. Because of the deficit in nurse-patient communication, the nurses disregarded the relentless experience of waiting endured by the participants.

Effective nurse-patient communication is largely accepted as an essential component of "good" nursing care. In contrast, the findings of my study showed that the level of nurse-patient communication and interaction on the haemodialysis unit was inadequate. Indeed, the technologically focused context of care on the haemodialysis unit meant the nurses concentrated almost entirely on the technical and physiological acts of care.

Based on these findings, a model of supportive care was recommended as one way to address the shortcomings of the current context of care on the haemodialysis unit at the study hospital. It is anticipated that the elements of supportive care would be introduced using a continuous quality improvement (CQI) framework. Overall, it is hoped that the findings of this research will inform nursing and healthcare practice and ultimately contribute to care that is effective and person-centred.¹⁵¹

¹⁵¹ To re-iterate, the use of the term 'person' in person-centred care refers to 'Dasein', the temporally situated human being who is constituted by his/her past, present, and future.

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APPENDIX A: PHYSIOLOGICAL COMPLICATIONS OF ESRD

There are various co-morbid conditions, which accompany ESRD. These conditions include diabetes, hypertension, cardiac disease, peripheral vascular disease, cerebrovascular disease, autoimmune diseases, renal carcinoma, haematological malignancies (e.g. myeloma, amyloidosis), and familial disease (e.g. polycystic kidney disease). Moreover, there are various disease-specific complications, which are also associated with the illness.

For instance, anaemia is present in many individuals with renal disease, which results in a loss of energy, fatigue, and breathlessness. The retention of water and sodium caused by renal disease induces breathlessness, pulmonary oedema, and generalised oedema of the feet, ankles, and around the eye area.

Uraemia disturbs gastrointestinal motility, which leads to poor appetite, inadequate nutritional intake, and nausea and vomiting. Renal osteodystrophy is the term used in the literature to describe the various forms of bone disease that occur as a consequence of renal disease. Renal bone disease is caused by altered calcium and phosphate regulation and results in pain and poor mobility. Pruritis or intense itching of the skin is also a common complaint for many patients.

Peripheral neuropathy is another symptom of ESRD and is deemed more common in men. The symptoms of peripheral neuropathy include severe pain and burning sensation in lower extremities, and restless leg syndrome. Restless leg syndrome is reported to be a very uncomfortable sensation that is relieved only through movement of the legs. It is more prominent at night and subsequently creates sleep disturbance for the person.

Pain is cited as a very common problem for ESRD patients and occurs because of their primary disease, concurrent co-morbid diseases, or the diseases caused by ESRD (e.g. renal bone disease). Pain is also specifically related to treatment with dialysis therapy.

Sleep disturbance is considered to affect up to half of dialysis patients. Insomnia is associated with pain, restless legs, and cramps. Both men and women with renal disease experience sexual disorders and dysfunction. These problems are caused both by the hormonal changes associated with renal disease and underlying diseases, such as diabetes and peripheral vascular disease.¹⁵²

¹⁵² This list of physiological complications is based on information by Brown, Chambers & Eggeling (2007), Ballinger & Patchett (2000), Ferro, Chambers & Davison (2004).

APPENDIX B: ACUTE COMPLICATIONS OF ESRD AND DIALYSIS

The acute physiological complications of ESRD arise from the excessive accumulation of fluid and harmful substances in the person's blood. These complications precipitate serious and sometimes life-threatening consequences for the person, including pulmonary overload, cardiac arrhythmia, and cardiac arrest. Furthermore, there are acute physiological complications specifically associated with dialysis therapy itself. The most common complications associated with peritoneal dialysis are peritonitis (infection of the peritoneum), infection of the peritoneal dialysis catheter (both exit site and catheter tunnel infection), and blockage of the catheter.

The acute complications associated with haemodialysis therapy include vascular access problems, such as poor blood flow, infection, thrombosis, and the pain of having needles inserted into arteriovenous fistulas and arteriovenous grafts. There are also complications that occur during the haemodialysis procedure itself. These commonly include hypotension, cramps, nausea, and vomiting. Hypotension and cramps occur due to the excessive removal of fluid and sodium during haemodialysis therapy. Hypotension can lead to nausea and vomiting.¹⁵³

¹⁵³ This list of acute complications associated with ESRD and dialysis therapy are based on information by Challinor (1998), Turner (1998), and Kotanko & Levin (2008).

APPENDIX C: OUTLINE OF CONFERENCE PRESENTATIONS

2008: *Lost Time: The patients' experience of waiting during haemodialysis therapy* presented at the International Nursing Research Conference of the Royal College of Nursing (RCN).

2007: *Waiting: The experience of patients on haemodialysis therapy* presented at the 8th Annual Interdisciplinary Research Conference at Trinity College Dublin.

2007: *Waiting: The experience of being a patient on haemodialysis therapy* presented at the International Nursing Research Conference of the Royal College of Nursing (RCN).

2006: *Waiting for a kidney transplant: The experience of being a patient on haemodialysis therapy* presented at the Health Research Board (HRB) Research Communication Awards. I was a finalist in the area of health services/systems research and population health.

2006: *Temporality and the experience of being a patient on haemodialysis therapy* presented at the 7th Annual Interdisciplinary Research Conference at Trinity College Dublin.

2006: *The experience of boredom for patients on haemodialysis therapy* presented at the International Nursing Research Conference of the Royal College of Nursing (RCN).

APPENDIX D: INFORMED CONSENT FORM

STUDY TITLE: An exploration of the illness experience of the patient with ESRD undergoing haemodialysis therapy.

RESEARCHER: Ms Aoife Moran

SUPERVISING CONSULTANT: Dr _____

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INFORMATION ABOUT THE STUDY

The purpose of this research is to explore your views and experience of being a patient on haemodialysis. The research is qualitative, which means that the researcher will gather information about your experience using interviews. The interviews will resemble a normal conversation and will be carried out, with your permission, on two occasions. During these interviews, you will be asked to talk about your experience of living with renal failure and haemodialysis. However, you are free to withhold any information you prefer not to discuss. If you decide during the study that you do not want to participate, you can withdraw at any time. This decision will not affect your treatment in any way.

The interviews, which will last for approximately an hour, will be recorded using a tape recorder to ensure that the researcher remembers everything that is discussed during the interview. The researcher will then transcribe (type) the interview. The information you provide during the interviews will be confidential. No information that identifies you will be included in the typed copy of your interview. Your name, and the name of others you mention, will be replaced by a code. The researcher does not need to look at your

medical records for this study. The taped interviews will be stored until the end of the study and then erased

It is hoped that the information from this study may help to determine the most useful ways for nurses to provide care to meet the needs of patients on haemodialysis. The final report, without any identifying information, may be presented or published with your permission.

AGREEMENT TO PARTICIPATE IN THE STUDY

This is to certify that I agree to participate in the above study. I am satisfied that there will be no risks to me resulting from participation in the study.

I hereby grant permission to be interviewed on two occasions and for these interviews to be recorded using a tape recorder. I understand that these interviews will be confidential, and that I will remain anonymous. I understand that I can withdraw from the study at any time, and my treatment will not be affected by this decision. I also grant permission for the final research report to be presented / published at the end of the study.

I am satisfied with the information I have received about the study. I have also had the opportunity to ask questions of the researcher, and all questions have been answered to my satisfaction.

Signature of Participant

Signature of Witness

Date

APPENDIX E: INSIGHTS FROM EXISTENTIAL LITERATURE

In hermeneutics, the spoken word is a powerful analytical and interpretive tool. Therefore, it is appropriate to bring insights from existential literature to bear on the findings of this study. This literature provides a complementary interpretive “lens” through which to view the participants’ experiences. Within this appendix, the participants’ experience of waiting will be discussed in relation to Franz Kafka’s (1999) novel *The Castle* and Samuel Beckett’s (1956) play *Waiting for Godot*. These literary works symbolised various characteristics of the participants’ experience of waiting, illustrated in the study.

Like the participants’ accounts of waiting, the fundamental existential moods of anxiety and boredom also formed the basis of the experience of waiting, presented by both writers. These moods highlighted the finitude of existence to the characters in the novel/play, and prompted them to live in either an authentic or inauthentic mode of existence. However, the experience of waiting meant the characters failed to live in either mode of existence.

If we recall, the inability to live in either mode of existence in response to anxiety and boredom created a disconnection in temporality. Moreover, it culminated in distressing moods for the person. Like the participants, the experience of waiting indefinitely meant the distressing moods intensified for the characters in the novel/play. The gradual progression of these distressing moods was conveyed in Kafka’s (1999) novel *The Castle*. However, the sense of fragmentation and series of incomplete narratives, which were threaded throughout the novel, never allowed these moods to intensify to an extreme level. In contrast, the acceleration of distressing moods was torturously palpable within Beckett’s (1956) play *Waiting for Godot*. Hence, it complemented Kafka’s work in providing a compelling insight into the participants’ experience of waiting, described in the study.

The Castle

It is suggested that the notion of waiting appeared to be both implicitly and explicitly revealed in Kafka's discourse throughout the novel *The Castle* (Kafka, 1999). The novel was based around a character called K. It began with K arriving in a village to start a job as a land surveyor in a castle that was situated in the village. K made his way to a nearby inn and sought accommodation for the night. However, when he arrived at the inn, it was clear that no one was expecting him. The landlord said he was unable to provide him with a room, and K was confined to the public bar where the peasants sat.

The landlord of the inn told K that the village belonged to the castle, and whoever stayed in the village must have a permit from the castle. As K did not have a permit, he began enquiries as to how he should get one. The rest of the novel was centred on K's endless wait for the castle to recognise his status as an official land surveyor.

In particular, K's experience of waiting for recognition from the castle seemed to mirror the participants' experience of waiting for a kidney transplant. When K arrived to the village, he was hopeful and looked forward to commencing a job as a land surveyor at the castle. However, regardless of his attempts to reach the castle, he never achieved this goal. Consequently, as K's wait to get to the castle continued indefinitely, his experience of hope turned to uncertainty.

The experience of uncertainty was threaded throughout the novel. Indeed, in the opening passage, we were immediately confronted with doubts as to whether the castle actually existed:

It was late in the evening when K. arrived. The village was deep in snow. The Castle hill was hidden, veiled in a mist and darkness, nor was there even a glimmer of light to show that a castle was there.

(Kafka, 1999, p277)

Kafka's repeated use of the words "certain" and "certainly" throughout the novel, completely contradicted the uncertainty, which infiltrated K's experience of waiting. Passages that began with certainty and hope frequently ended in uncertainty and doubt. Like the participants' experience of waiting for a transplant, there were many examples throughout the novel where K's hopes of getting to the castle were continuously undermined by uncertainty.

For instance, the arrival of Barnabas, with a message from the castle, provided K with some hope.¹⁵⁴ It informed K to meet the superintendent of the village who would give him the details of his employment. However, when K met the superintendent, he was advised that there had been a miscommunication between the official departments of the castle. Therefore, the castle did not require a land surveyor after all. At this point, K's experience of uncertainty was expressed. After making the long journey to take on the job as land surveyor in the castle, K questioned the superintendent, as to why this injustice had occurred: "But how is this possible?" cried K. "Surely I haven't made this endless journey just to be sent back again" (Kafka, 1999, p309).

When the superintendent responded by providing K with a long-winded and ambiguous account of why the confusion had occurred, K replied: "So the only remaining conclusion...is that everything is very uncertain and insoluble, including my being thrown out" (Kafka, 1999, p317).

The uncertainty, which was illustrated in K's experience of waiting, was characteristic of the participants' experience of uncertainty, while they waited for a kidney transplant. If we recall, the participants understood that they would receive a kidney transplant within a specific duration of time. However, when they exceeded this time frame, they became uncertain. Their experience of uncertainty turned their hope of receiving a kidney transplant, to disappointment and despair. Without a definite possibility of receiving a transplant, the participants began to speculate whether the wait would ever end.

As mentioned previously, the participants' experience of uncertainty represented Heidegger's (1962) description of anxiety.¹⁵⁵ It highlighted the threefold structure of originary temporality to the participants, and subsequently disclosed the possibility of death. Thus, the participants were prompted to live in either an authentic or inauthentic mode of existence.

¹⁵⁴ Barnabas was a messenger for the castle.

¹⁵⁵ See page 195 for the discussion on anxiety in relation to the theme *Waiting for a Kidney Transplant*.

It is suggested, that like the participants, the experience of uncertainty, also disclosed the finitude of existence to K. This prompted him to live in either an authentic or inauthentic mode of existence. However, K's possibilities for the future seemed to depend entirely on his status being recognised by the castle. Since this recognition did not occur throughout the entire novel, K was unable to live in the authentic mode of existence. Moreover, the failure of the castle to recognise K's status meant he was unable to engage in his everyday activities as a land surveyor. These features of K's experience implied that while he waited for recognition by the castle, he was unable to absorb himself in the everydayness of the inauthentic mode of existence.

Similarly, the participants' accounts of waiting for a kidney transplant suggested they were unable to live in either the authentic or inauthentic mode of existence, when confronted with their finite existence. The uncertainty of waiting indefinitely for a kidney transplant meant they were unable to visualise possibilities in the future. Furthermore, the restrictions of haemodialysis therapy meant they were unable to participate in the everyday activities, which they took for granted in the past. Therefore, they described their experience of being on hold, while they waited for a kidney transplant. The participants' experience of being on hold represented a disconnection in ordinary temporality, which culminated in profound boredom.¹⁵⁶

It is proposed, that K's inability to live in either mode of existence when faced with the possibility of death, also created a disruption to ordinary temporality, which led to profound boredom. To briefly summarise, Heidegger (1995) described boredom as a fundamental existential mood. Like anxiety, it disclosed the person's finite existence.¹⁵⁷ There were three forms of boredom, which ranged from the most superficial to the most profound. The third form of boredom was the origin of the other two, because it disclosed the person's finite existence. Therefore, the person tried to flee or escape from the first and second forms of boredom to avoid being drawn into the third and most profound form of boredom (Heidegger, 1995).

¹⁵⁶ See page 200 for the discussion on the disconnection in ordinary temporality/profound boredom represented in the participants' experience of being on hold.

¹⁵⁷ See pages 125 for a more in-depth discussion on Heidegger's perspective of boredom.

As previously mentioned, the participants' descriptions of waiting, described in the themes *Lost Time* and *Waiting for Kidney Transplant* suggested they were unable to flee from the first and the second forms of boredom.¹⁵⁸ Hence, they oscillated into profound boredom. Like the participants in the study, it seemed that K was also unable to flee from the first and second forms of boredom, while he waited for recognition of his status from the castle. As a result, it seemed he progressed into the third and most profound form of boredom, described by Heidegger (1995).

According to Heidegger (1995), the first form of boredom involved becoming bored by something. Heidegger claimed that this form of boredom occurred if we were forced to wait in a particular situation. K was forced to wait in the village until the castle decided to recognise his status. The experience of being forced to wait in the village implied that K might have experienced the first form of boredom, described by Heidegger (1995). Likewise, the participants in my study had no option except to wait for a kidney transplant. As a result, they also experienced the first form of boredom.

The first form of boredom was accompanied by impatience and uneasiness (Heidegger, 1995). The experience of impatience, uneasiness, frustration, and anger were contained within the participants' accounts of waiting. Correspondingly, the impatience, uneasiness, and frustration caused by K's experience of waiting were also portrayed within the novel.

For instance, in the following passage, K found out that Barnabas, the messenger had not delivered his previous message to the castle. Instead, Barnabas had been working as an assistant to his father, the cobbler in the village. K's impatience and frustration were palpable in his following dialogue with Barnabas:

K. bit his lip with impatience. "Sir," replied Barnabas...I'll certainly see to it, and I'll certainly see to the message you gave me last time as well."
"What!" cried K., "haven't you seen to that [message] yet then? Weren't you at the Castle next day?" "No,"replied Barnabas, "my father is old, you've seen him yourself, and there happened to be a great deal of work just then, I had to help him, but now I'll be going to the Castle again soon." "But what are you thinking of, you incomprehensible fellow?" cried K., beating his brow with his fist... "You're in an important

¹⁵⁸ See pages 158 and 198 for the discussion on the participants' experience of waiting in relation to the three forms of boredom.

position, you're a messenger, and yet you fail me in this wretched manner! What does your father's work matter?...And who can need boots here in these eternally empty streets?" (Kafka, 1999, p343-344).¹⁵⁹

It is proposed, that while K waited for recognition from the castle, he was left empty by the village. This was implicitly expressed in the passage above when K referred to the "eternally empty streets" of the village. According to Heidegger (1995), being left empty by things was a feature of the first form of boredom. He stated that being left empty occurred when we exceeded the appropriate time for a particular thing. From Heidegger's (1962) perspective, everything we engaged with in world-time lasted for a particular duration of time. However, if we exceeded the duration of time, which was appropriate for a specific thing, it left us empty. The castle's delay in recognising K's status meant he was forced to wait in the village much longer than he had initially anticipated. Therefore, while K waited relentlessly for the castle's recognition, the village left him empty. K's experience of being left empty by the village depicted the first form of boredom, described by Heidegger (1995).

In a similar way, the participants' accounts of waiting, presented in the sub theme *Wasting Time* illustrated that they spent a significant duration of time waiting unnecessarily before and after dialysis therapy. The time spent waiting prevented the participants from engaging in their everyday lives and activities. Therefore, while they waited needlessly, the haemodialysis unit essentially offered them nothing and left them empty.

Based on Heidegger's interpretation, the first form of boredom was transitory (Aho, 2007). In other words, when persons escaped from the thing that was boring them, they were also able to flee from the first form of boredom. The participants' accounts of waiting, described in the themes *Lost Time* and *Waiting for a Kidney Transplant* conveyed that they experienced the first form of boredom, described by Heidegger (1995).¹⁶⁰ The ongoing nature of their experience of waiting meant they were unable to flee from the first form of boredom. Hence, they progressed into the second form of boredom, described by Heidegger (1995).

¹⁵⁹ The use of three spaced ellipsis points (...) within this block quotation indicates that some material has been omitted from the original source.

¹⁶⁰ See pages 158 and 198 for the discussion on the participants' experience of boredom in relation to both themes.

Correspondingly, K's story indicated that he had to continuously wait in the village, since the castle persistently failed to recognise his status. This signified that he was also unable to flee from the first form of boredom. Like the participants in my study, it is proposed that K advanced into the second form of boredom, described by Heidegger (1995).

According to Heidegger (1995), the second form of boredom involved being bored with something that was unfamiliar and indeterminate. The "something" unfamiliar and indeterminate, which bored the person in the second form of boredom, was the standing of world-time. Based on Heidegger's (1995) account, world-time was normally understood as something that flowed. Therefore, when world-time came to a stand, it became something unfamiliar and indeterminate. It was the standing of world-time, as distinct from flowing, that bored one in the second form of boredom.

While K waited for recognition from the castle, he was unable to participate in his everyday occupation as a land surveyor. As mentioned previously, world-time was the time, which contained our everyday activities and involvements in the world. Hence, when these activities were suspended or stopped, world-time subsequently came to a stand. It seemed that K's inability to participate in his everyday work as a land surveyor brought world-time to a stand. This standing of world-time was indicative of the second form of boredom, presented by Heidegger (1995).

If we recall, the participants' accounts of waiting, described in the sub themes *Killing Time*, *Wasting Time*, and *Being on Hold* also epitomised the standing of world-time, which was characteristic of the second form of boredom.¹⁶¹ The participants' descriptions of waiting, illustrated within these sub themes implied that they were held back from their everyday lives and activities. Thus, world-time was brought to a stand by their experience of waiting, which subsequently culminated in the second form of boredom, advanced by Heidegger (1995). The continuous nature of the participants' experience of waiting meant they were unable to flee from the second form of boredom. Therefore, they were drawn into the third and most profound form of boredom, described by Heidegger (1995).

¹⁶¹ See pages 158 and 198 for the discussion of these sub themes in relation to boredom.

Like the participants in the study, K's experience of waiting indefinitely for recognition from the castle confirmed that he was unable to flee or overcome the second form of boredom. This suggested that K may have progressed into the third and most profound form of boredom, described by Heidegger (1995).

If we recall, in the third form of boredom, originary temporality was suspended (Heidegger, 1995). Therefore, the unified structure of originary temporality was dissolved, and the present was disconnected from the future. In profound boredom, the person was held in limbo by the suspension of originary temporality. When held in limbo by the suspension of originary temporality, individuals were held back from their own possibilities in life, and were subsequently held back from their past and future (Haar, 1999).

Throughout the novel, we were given the impression that the unified structure of originary temporality may be disconnected for K. For instance, we were given no solid or reliable information about K's past life experience. While we were told he was a land surveyor, there was no information as to how he came to acquire these skills, or where he had previously worked.

There were times within the novel when K made fleeting statements about his native town, and his days as a soldier (Kafka, 1999, p286). However, there was no contextual or supplementary information about these elements of his past life. Furthermore, until K attained recognition of his status as a land surveyor from the castle, he appeared to have no future possibilities either. For the most part, we were given the impression that K's current experience of life in the village was entirely severed from his past and future. This was emphasised in the following passage of the novel:

K. was haunted by the feeling that he was losing himself or wandering into a strange country, farther than ever man had wandered before, a country so strange that not even the air had anything in common with his native air, where one might die of strangeness, and yet whose enchantment was such that one could only go on and lose oneself further (Kafka, 1999, p299).

The passage implied that K's past experience of life in his native homeland was so disconnected from his current experience of living in the village, that both places did not share the same air. In addition, he could not contemplate future possibilities until the castle recognised his status as land surveyor. These characteristics of K's experience conveyed that he was held in limbo by the suspension of originary temporality.

According to Heidegger (1962), when the unified structure of originary temporality was disconnected, it illuminated the threefold structure of originary temporality to the person. This highlighted death as one possibility of the person's existence.¹⁶² The reference to death in the above passage from the novel (p299) symbolised how the disconnection in originary temporality disclosed the possibility of death to K.

The disruption in originary temporality created by K's experience of waiting was characteristic of the participants' descriptions of being on hold, while they waited for a kidney transplant. The unrelenting wait for a kidney transplant meant the participants were unable to contemplate possibilities for the future. In addition, the restrictions of haemodialysis therapy prevented them from engaging fully in the everyday life they took for granted in the past. Therefore, the participants' described their experience of being on hold, while they waited for a kidney transplant. It was suggested that their experience of being on hold represented a disconnection in the unified structure of originary temporality.¹⁶³

The participants' experience of being on hold while they waited for a kidney transplant conveyed that they were not acting in world-time to project forward into possibilities in the future. Instead, they were held back in a time that was essentially separated from the narrative of their lives. This corresponded with Heidegger's (1995) description of profound boredom. The suspension of originary temporality, which occurred in profound boredom held the person back from world-time (Haar, 1999, p299).

Similarly, the suspension of originary temporality caused by K's experience of waiting also seemed to prevent him from acting in world-time. For instance, after much

¹⁶² See pages 164 and 200 for the discussion of profound boredom in relation to the participants' experience of waiting.

¹⁶³ See page 200 for discussion of experience of being on hold in relation to the third form of boredom, described by Heidegger (1995).

consideration, and encouragement from his fiancée Frieda, K decided to take the job of janitor in the village school.¹⁶⁴ This meant that K, Frieda, and two assistants had to live and work in the school. On the first night in the school, they were cold and decided to light a fire. However, to get wood for the fire, K had to break into the school shed. The following morning, the head teacher arrived and was furious that K had broken into the shed. In his anger, the teacher gave K notice to leave the job.

K replied:

You're my superior, but not the person who engaged me for this post; it was the Superintendent who did that, and I'll only accept notice from him. And he certainly never gave me this post so that I and my dependents should freeze here, but – as you told me yourself – to keep me from doing anything thoughtless or desperate (Kafka, 1999, p351).

K's decision to commence the job as school janitor gave us the impression that he was attempting to engage in world-time, while he waited for recognition from the castle. By engaging in world-time, K would be able to live in the inauthentic mode of existence. He would have been able to act in world-time (originary present) in order to project forward into possibilities in the originary future. Consequently, this would have allowed him to reconnect the threefold structure of originary temporality, and in turn overcome profound boredom.

However, the above excerpt from the novel highlighted that K was not acting in world-time, to project forward into possibilities in the future. He was a land surveyor and came to the village to work for the castle in this capacity. The job of school janitor was neither related to K's originary past nor his originary future.¹⁶⁵ This implied that originary temporality was suspended or frozen for K, while he was forced to work as janitor in the school. Therefore, the word "freeze" in the above passage could be taken literally to mean freeze with the cold. However, in light of the current interpretation, the word freeze may have also implied that originary temporality was frozen or suspended for K, while he waited for recognition by the castle.

¹⁶⁴ Frieda was a barmaid at an inn in the village. She had become K's fiancée since his arrival to the village. Frieda had connections with Klamm, an authoritative figure in the castle. Therefore, throughout the novel, we were left wondering if this was the reason why K was so quick to develop a close relationship with Frieda.

¹⁶⁵ See page 93 for the previous discussion on originary temporality.

The notion of time being frozen or suspended symbolised the participants' experience of being on hold, while they waited for a kidney transplant. The participants' experience of being on hold was portrayed as being held back or suspended in a time that was effectively severed from the narrative of their lives.

According to Heidegger (1995), when originary temporality was suspended, as was the case in profound boredom, the person was no longer acting in the present to project forward into possibilities in the future. Instead, the present was characterised by inaction, and the person was compelled to endure empty time. This was the empty time of profound boredom. The empty time of boredom did not imply that the person ceased to act. Rather, the person was no longer acting in the originary present to project forward into possibilities in the future. Consequently, the lack of purposeful action in the originary present (world-time) signified that the originary present was empty. Heidegger described this empty present, as the empty time of profound boredom (Haar, 1999).

If we recall, the participants' descriptions of waiting, provided in the sub themes *Being on Hold*, *Killing Time*, and *Wasting Time* highlighted that they were not acting in world-time (originary present) to project forward into possibilities in the future. Thus, they endured the empty time of profound boredom.¹⁶⁶ Similarly, it seemed from the previous passage from the novel *The Castle* that K was enduring the empty time of profound boredom, while he stayed in the job as school janitor. He was not acting in world-time to project forward into possibilities in the future. Indeed, there was very little evidence that K performed any tasks or activities in his job as school janitor. Even after the head teacher threatened to dismiss K, he still failed to perform any activities: "Work completely stopped, the breakfast lingered on unconsciously" (p356).

Nevertheless, K's ultimate possibility was to be recognised as land surveyor by the castle. Until then, he was compelled to endure the empty time of profound boredom, while he remained in the job as school janitor. From K's perspective, this was the only way to bring his ultimate possibility to fruition.

¹⁶⁶ See pages 133, 144, and 185 for the discussion of these themes in relation to boredom.

For this reason he [K] must try to keep his post which gave Frieda a certain degree of security, and he must not complain if for this end he were made to endure more at the teacher's hands than he would have had to endure in the ordinary course. All that sort of thing could be put up with, it belonged to the ordinary continual petty annoyances of life, it was nothing compared with what K was striving for, and he had not come here simply to lead an honoured and comfortable life (Kafka, 1999, p361).

Like K, the participants' accounts of waiting, described in my study illustrated they had no choice but to endure the empty time of profound boredom. For example, their accounts of being on hold signified that they were unable to visualise possibilities in the future until they received a kidney transplant. They were subsequently unable to engage fully in an everyday life due to the restrictions of the dialysis treatment regime. Therefore, the participants were not acting in the present to project forward into possibilities in the future. Instead, they were held back in the empty time of profound boredom.

Moreover, the participants descriptions of waiting, presented in the theme *Lost Time* also conveyed the empty time of profound boredom. The participants had to repeatedly endure the experience of waiting each time they attended haemodialysis therapy. This created a disruption to world-time, which meant they were unable to act in the present in order to project forward into possibilities in the future. Consequently, the experience of incessantly waiting meant they were forced to endure the empty time of profound boredom.

The follow-up interview highlighted that some participants eventually managed to live in the inauthentic mode of existence, which enabled them reconnect the threefold structure of ordinary temporality. These participants were able to overcome the profound boredom caused by their experience of waiting. Conversely, several participants' expressed their inability to live in either an authentic or inauthentic mode of existence in response to boredom. If we recall, the inability to live in either mode of

existence resulted in unpleasant and distressing moods.¹⁶⁷ These distressing moods were threaded throughout the participants' accounts of waiting, and included uneasiness, irritation, frustration, disappointment, depression, and despair. The ongoing nature of the experience of waiting meant that some participants were persistently unable to live in either mode of existence in response to boredom. As a result, the unpleasant and distressing moods developed and intensified over time.

Similarly, K never received recognition of his status from the castle and had to relentlessly endure the experience of waiting, throughout the novel. K's story exemplified how the relentless wait made it impossible for him to live in either an authentic or inauthentic mode of existence. Thus, K's distressing moods gradually heightened as the wait continued. However, the series of fragmented and incomplete narratives, which formed the basic style of the novel, meant the unpleasant moods experienced by K were never allowed to intensify to an extreme level.

In contrast, the accelerating distress, which occurred when the person was persistently unable to live in either mode of existence was captured vividly by Beckett (1956) in his play *Waiting for Godot*. Furthermore, the existential moods of anxiety and boredom, which were embedded within the participants' experience of waiting, were also exemplified within the play. In the following account, the participants' experience of waiting will be discussed in relation to Beckett's play *Waiting for Godot*.

Waiting for Godot

“Have you not done tormenting me with your time!” (Pozzo, Act 11, p 82)

There are two acts in Beckett's (1956) play *Waiting for Godot*. Act 1 begins in the evening on a country road, where two men named Vladimir and Estragon wait by a tree for the arrival of someone called Godot. Estragon is an old man sitting on a low mound trying to remove his boot, and Vladimir is another old man who chats to him. Estragon appears to have been beaten. The two men are homeless and debilitated. They apparently know each other for years and were possibly respectable in the past. While they wait and engage in conversation to pass the time, two strangers arrive: a landowner

¹⁶⁷ See page 125 for the previous discussion on Heidegger's account of the fundamental existential mood of boredom.

called Pozzo, and at the end of a rope, a slave called Lucky. When commanded by Pozzo, the slave dances and thinks aloud to entertain the others. After Pozzo and Lucky move on, a messenger boy enters and announces that Godot will not arrive this evening, but “surely tomorrow”. When the messenger boy leaves, Estragon suggests to Vladimir that they should commit suicide. Although the two characters debate whether they should give up the wait for Godot and leave, they do not go anywhere.

In Act 11, Vladimir and Estragon resume their wait by the tree. The action is almost the same as in the first act of the play. The men continue to pass the time, while they wait for Godot. The tree has sprouted leaves. Pozzo and Lucky return, except this time the landowner Pozzo is blind and helpless, and Lucky is mute. After Pozzo and Lucky depart, the messenger boy arrives with the same message as before. Estragon and Vladimir again consider suicide, but when they test Estragon’s belt as a suicide instrument, it breaks. Therefore, the two characters again decide to continue the wait for Godot.

It is proposed, that Vladimir and Estragon’s experience of waiting for Godot, depicted certain characteristics of the participants’ experience of waiting, described in my study. For instance, in the play *Waiting for Godot*, Godot acted as a concept or idea of hope and expectation for Vladimir and Estragon (Graver, 2004). We were given the impression that the arrival of Godot would provide the two characters with the possibility of a better future. Therefore, the play revolved around Vladimir and Estragon’s relentless wait for this hope to arrive. Similarly, the participants in my study described their experience of living in hope, while they waited for a kidney transplant.¹⁶⁸ The hope of receiving a kidney transplant provided them with the possibility of returning to a normal life in the future.

As the wait for Godot continued indefinitely, Vladimir and Estragon experienced uncertainty. Indeed, the experience of uncertainty was threaded throughout the play. The following dialogue between the two characters provided one example of this uncertainty, as Estragon began to question Vladimir as to whether they were waiting at the right place:

¹⁶⁸ See page 173 for the theme *Living in Hope*.

Vladimir: We're waiting for Godot.
 Estragon: [*Despairingly*] Ah! [*Pause.*] You're sure it was here?
 Vladimir: What?
 Estragon: That we were to wait.
 Vladimir: He said by the tree. [*They look at the tree.*] Do you see any others?
 Estragon: What is it?
 Vladimir: I don't know. A willow.
 Estragon: Where are the leaves?
 Vladimir: It must be dead.
 Estragon: No more weeping.
 Vladimir: Or perhaps it's not the season.
 Estragon: Looks to me more like a bush.
 Vladimir: A shrub.
 Estragon: A bush.
 Vladimir: A - . What are you insinuating? That we've come to the wrong place?
 Estragon: He [Godot] should be here.
 Vladimir: He didn't say for sure he'd come.
 Estragon: And if he doesn't come?
 Vladimir: We'll come back tomorrow.
 Estragon: And then the day after tomorrow.
 Vladimir: Possibly (Beckett, 1956, p6).

The uncertainty experienced by Vladimir and Estragon, while they waited for Godot seemed to characterise the uncertainty experienced by the participants, while they waited for a kidney transplant. If we recall, the participants' experience of uncertainty represented Heidegger's (1962) description of anxiety.¹⁶⁹ From Heidegger's perspective, anxiety was a fundamental existential mood.¹⁷⁰ It illuminated the threefold structure of originary temporality to the participants. This subsequently disclosed the possibility of death to the participants and prompted them to live in either an authentic or inauthentic mode of existence.¹⁷¹

Correspondingly, Heidegger's interpretation of anxiety and boredom as fundamental existential moods was also conveyed throughout the play *Waiting for Godot* (Beckett, 1956). For example, Vladimir's statement "One isn't master of one's moods" (p50) implied that moods were not subjective, private mental states. Instead, throughout the play, moods arose out of the character's being-in-the-world i.e. their everyday relating

¹⁶⁹ See page 195 for the previous discussion of the participants' experience of uncertainty/anxiety.

¹⁷⁰ See pages 123-124 for the previous discussion on Heidegger's perspective of moods.

¹⁷¹ By existing authentically, I am aware of the finitude of my existence, but still project forward into possibilities in the originary future. In the inauthentic mode of existence, I do not acknowledge my finite nature. Instead, I allow myself to be absorbed in the everyday tasks and activities, which occur in world-time to avoid this realisation. The threefold structure of originary temporality remains unified in both modes of existence.

or comportment with the things, and people in the world. Thus, common everyday activities such as putting on boots and hats, engaging in idle talk, eating, and eliminating occurred at the same time as moods such as hope, uncertainty, disappointment, and despair.

Like the participants in the study, it is suggested that the experience of uncertainty disclosed the possibility of death to Vladimir and Estragon. When the possibility of death was disclosed to the two characters they were prompted to live in either an inauthentic or authentic mode of existence. However, Vladimir and Estragon's experience of waiting signified that they were unable to live in either mode of existence, when confronted with the reality of death. Their future possibilities seemed to depend entirely on the arrival of Godot. Thus, until he arrived, they had no possibilities for the future, and were unable to live in the authentic mode of existence.

Furthermore, their experience of waiting suggested they were also unable to live in the inauthentic mode of existence. In the inauthentic mode of existence, the person was absorbed in the everyday tasks and activities performed in world-time. These activities were performed in order to project forward into possibilities in the future. Therefore, the activities were productive and had an outcome.

Vladimir and Estragon's experience of waiting for Godot signified that they were not acting in world-time to project forward into possibilities in the future. Instead, they were held back from engaging in an everyday life, while they waited for Godot. The time spent waiting appeared to be empty and unproductive for the two characters. Therefore, Estragon's statement "nothing to be done" in the opening passage set the scene for the entire play. It suggested that while the two characters waited for Godot, nothing productive would be accomplished.

It is proposed, that Vladimir and Estragon's inability to live in either an authentic or inauthentic mode of existence culminated in a disruption to the unified structure of ordinary temporality. Indeed, throughout the play, there was verification that the threefold structure of ordinary temporality was disconnected for the two characters. Their future possibilities seemed to depend entirely on the arrival of Godot. Therefore,

they were not projecting forward into possibilities in the future, while they waited indefinitely for his arrival.

In addition, there was a great deal of doubt surrounding the characters' past. For instance, when the play began, we assumed that the two characters had just met. However, as the play progressed, we were led to suspect that the characters had waited for Godot many times in the past with little results. The degree of familiarity between the characters was highlighted when they suddenly began to call each other Didi and Gogo. However, apart from these hints, we were given no concrete information in relation to the characters' past. Therefore, while they waited for Godot's arrival, the threefold structure of originary temporality seemed to be held back or disconnected for Vladimir and Estragon.

Similarly, the narratives of the participants in my study illustrated that they were unable to live in either an authentic or inauthentic mode of existence, while they waited for a kidney transplant. The uncertainty of waiting indefinitely for a transplant meant the participants were unable to project forward into possibilities in the future. In addition, the restrictions of haemodialysis therapy prevented them from performing the everyday activities they took for granted in the past. As a result, they described their experience of being on hold, while they waited for a kidney transplant. The participants' experience of being on hold represented a disconnection in the threefold structure of originary temporality.¹⁷² This disconnection in originary temporality culminated in profound boredom, as described by Heidegger (1995).¹⁷³

As previously mentioned, Heidegger (1962) described boredom as a fundamental existential mood, which highlighted the finitude of our existence.¹⁷⁴ There were three forms of boredom, ranging from the most superficial to the most profound. If the person were able to escape or flee from the first and second forms of boredom, s/he would not progress into the third and most profound form of boredom (Heidegger, 1962).

¹⁷² See page 200 for the previous discussion on the disconnection of originary temporality represented in the participants' experience of being on hold.

¹⁷³ See page 158 for the previous discussion on Heidegger's description of boredom.

¹⁷⁴ See page 125 for Heidegger's discussion of boredom as a fundamental existential mood.

The participants' accounts of waiting, illustrated in the themes *Lost Time* and *Waiting for Kidney Transplant* implied they were unable to flee from the first and the second forms of boredom. Hence, they oscillated into the third form of boredom.¹⁷⁵ Like the participants in the study, Vladimir and Estragon's experience of waiting for Godot seemed to convey certain features of the first and second forms of boredom, advanced by Heidegger (1995). Their experience of "time dragging" and "killing time" signified that they experienced the first form of boredom.

While Vladimir and Estragon waited indefinitely for Godot, the time seemed to drag. Therefore, throughout the play, the characters used various strategies to kill time while they waited. They talked to each other, sang, shared stories, ate and slept. When Pozzo and Lucky arrived, they entertained the two characters, which also enabled them to kill time. However, as the play progressed, there was evidence that the strategies used by the two characters to kill time, were less successful. This was highlighted in the following section of the play, which appeared in Act 1 after Pozzo and Lucky departed:

Vladimir: That passed the time.
Estragon: It would have passed in any case.
Vladimir: Yes, but not so rapidly. [*Pause.*]
Estragon: What do we do now?
Vladimir: I don't know.
Estragon: Let's go
Vladimir: We can't.
Estragon: Why not?
Vladimir: We're waiting for Godot.
Estragon: [*Despairingly*] Ah! [*Pause.*] (Beckett, 1956, p41).

Vladimir and Estragon's experience of killing time, while they waited for Godot appeared to characterise the participants' experience of killing time during haemodialysis therapy.¹⁷⁶ The activities used by the participants did not enable them to effectively kill time for the entire duration of haemodialysis therapy. Hence, they spent a lot of time merely waiting for the treatment to end. The impatience, uneasiness, irritation and frustration were depicted within their accounts of killing time. These distressing moods were also portrayed as a feature of the first form of boredom, advanced by Heidegger (1995).

¹⁷⁵ See pages 158 and 198 for the discussion on the participants' experience of waiting in relation to the three forms of boredom.

¹⁷⁶ See page 133 for sub theme Killing Time.

Likewise, Vladimir and Estragon's inability to kill time meant they were unable to flee from the distressing experience of waiting indefinitely for Godot. Consequently, the uneasiness, irritability, frustration, and anger were also contained within their experience of waiting. For instance, in the following dialogue, Estragon expressed the feelings of frustration and anger caused by the experience of prolonged waiting. The dialogue appeared in Act 1, when the messenger boy entered to tell the two characters that Godot would not arrive until tomorrow.

Estragon: [*Violently.*] Will you approach! [*The boy advances timidly.*]

What kept you so late?

Vladimir: You have a message from Mr Godot?

Boy: Yes, sir.

Vladimir: Well, what is it?

Estragon: What kept you so late? [*The boy looks at them in turn, not knowing to which he should reply.*]

Vladimir: [*To Estragon.*] Let him alone.

Estragon: [*Violently.*] You let me alone! [*Advancing, to the boy.*] Do you know what time it is?

Boy: [*Recoiling.*] It's not my fault, sir.

Estragon: And whose is it? Mine?

Boy: I was afraid, sir.

Estragon: Afraid of what? Of us? [*Pause.*] Answer me!

(Beckett, 1956, p42-3).

The participants in my study had no option but to wait for a kidney transplant. Hence, the experience of persistently waiting meant they unable to flee from the first form of boredom. Correspondingly, it is proposed that Vladimir and Estragon's ongoing experience of waiting for Godot also hindered their ability to escape from the first form of boredom. Thus, like the participants in the study, the two characters in the play were drawn into the second form of boredom, described by Heidegger (1995).

According to Heidegger (1995), in the second form of boredom we were held in limbo by the standing of world-time. As mentioned earlier, Vladimir and Estragon's experience of waiting for Godot prevented them from engaging in everyday activities. The activities they performed to kill time, were not the same as the absorbed everyday activities one normally performed in world-time. They did not have a specific outcome or purpose. These aspects of the characters' experience of waiting indicated that world-time had come to a stand for the two characters. It subsequently implied that while they

waited for Godot, they endured the second form of boredom, described by Heidegger (1995).¹⁷⁷

In the same way, the sub themes *Killing Time*, *Wasting Time* and *Being on Hold* highlighted that the participants were essentially held back from engaging in everyday activities, as a result of their experience of waiting.¹⁷⁸ This signified that world-time had come to a stand for the participants. In addition, the relentless and repetitive nature of their experience of waiting made it difficult to overcome the standing of world-time. Hence, the participants were unable to flee from the second form of boredom, and proceeded into the third and most profound form of boredom, presented by Heidegger (1995).

Vladimir and Estragon's incessant wait for Godot meant they were also unable to overcome the standing of world-time. Therefore, like the participants in the study, the two characters were unable to escape from the second form of boredom, and progressed into profound boredom.

The third and most profound form of boredom, advanced by Heidegger (Heidegger, 1995) was represented in the play *Waiting for Godot*. If we recall, in Heidegger's description of profound boredom, the person was held in limbo by the suspension of ordinary temporality. Therefore, ordinary temporality was suspended or stopped. There were various passages in the play, which suggested that ordinary temporality was stopped for Vladimir and Estragon.

The following section appeared in Act 2, when Pozzo and Lucky returned. Pozzo was no longer the powerful landowner with Lucky as his slave. Instead, Pozzo was blind and was led by Lucky, who was now dumb, and on a shorter rope. Lucky fell to the ground and brought Pozzo with him. Pozzo lay pleading to Vladimir and Estragon to help him to get up after his fall:

¹⁷⁷ In the second form of boredom, world-time comes to a stand.

¹⁷⁸ See these sub themes on pages 133, 144, and 185.

Pozzo: Help!

Vladimir: Do you hear him?

Estragon: We are no longer alone, waiting for the night, waiting for Godot, waiting for...waiting. All evening we have struggled, unassisted. Now it's over. It's already tomorrow.

Pozzo: Help!

Vladimir: Time flows again already. The sun will set, the moon will rise, and we away...from here (Beckett, 1956, p69).¹⁷⁹

Vladimir's description of "time flowing again", confirmed that time was previously held back or suspended for the two characters, while they waited for Godot. As mentioned previously, the future had priority in originary temporality because it gave the threefold structure of originary temporality its projective features.¹⁸⁰ Therefore, Vladimir's predominant focus on the future in the section above implied that he was referring to originary temporality.

The passage suggested that Vladimir possibly viewed the return of Pozzo and Lucky as a way to overcome the empty time of profound boredom. By assisting Pozzo and Lucky up after their fall, the two characters would have temporarily absorbed themselves in the inauthentic mode of existence. In turn, this would have allowed the threefold structure of originary temporality to be reconnected and time would "flow again". Consequently, Vladimir eagerly invited Estragon to do something to help Pozzo instead of wasting time engaging in idle conversation.

Let us not waste our time in idle discourse! [*Pause. Vehemently.*] Let us do something, while we have the chance! It is not everyday that we are needed (Beckett, 1956, p71).

According to Heidegger, the third form of boredom gave one the disheartening feeling of wasting time (Haar, 1999). The experience of wasting time emerged from the realisation that the person was ultimately wasting the finite time allotted to his/her existence (Heidegger, 1995). Like the two characters in the play, the participants' experience of wasting time was implicitly and explicitly contained in the sub themes *Wasting Time* and *Killing Time*.

¹⁷⁹ The use of three spaced ellipsis points (...) within the quotations taken from the play *Waiting for Godot*, were contained in the original source.

¹⁸⁰ See page 94 for the previous discussion on the originary future.

When the threefold structure of ordinary temporality was suspended, the person was not acting in the ordinary present in order to project forward into possibilities in the ordinary future. Rather the present was characterised by inaction, and the person endured the empty time of profound boredom. The empty time of profound boredom led to nothing but a repetition of the same present (Haar, 1999). The participants' descriptions of waiting, in the themes *Lost Time* and *Waiting for a Kidney Transplant* indicated that they were compelled to endure the empty time of profound boredom.¹⁸¹

Similarly, Vladimir and Estragon's experience of waiting for Godot characterised the empty time of profound boredom. Throughout the play, it seemed apparent that the characters were not acting in the present to project forward into possibilities in the future. Indeed, this was emphasised by Estragon in Act 1, when he exclaimed, "Nothing happens, nobody comes, nobody goes, it's awful!" (Beckett, 1956, p34). Furthermore, the series of repetitive routines or rituals, which constituted the basic structure the play (Graver, 2004), were indicative of the repetitive empty present, which was synonymous with profound boredom.

As previously mentioned, Heidegger (1995) contended that profound boredom disclosed the finitude of our existence.¹⁸² Throughout the play *Waiting for Godot*, we were regularly confronted with the stark reality that existence was finite. This was implicitly contained in the speech by Lucky (Beckett, 1956, p36-38).

Lucky appeared to be a pitiful creature who was incapable of talking, never mind making a speech. However, his speech, which at first seemed like unintelligible ramblings, served to confront us with a central idea of the play - that we were all finite beings. The use of phrases such as "labours abandoned", "labours left unfinished", "man in short", "man in brief", "waste and pine", "shrink and dwindle", left us with no doubt that Lucky's ambiguous rant was providing a clear message about the finitude of our existence.

Moreover, the entire play consisted of Vladimir and Estragon's desperate attempts to continuously engage in conversation and pastimes, in an effort to avoid reflecting on the

¹⁸¹ See pages 164 and 200 for the discussion of profound boredom in relation to both themes.

¹⁸² See page 125 for previous discussion on profound boredom as a fundamental existential mood.

finitude of their existence. However, as depicted in the following section of the play, it was impossible for the two characters to maintain the incessant conversation, while the wait for Godot continued indefinitely. Thus, they were unable to block out the grim reality of the finitude of existence, disclosed by profound boredom.

Vladimir: To every man his little cross. [*He sighs*]. Till he dies [*Afterthought*].
And is forgotten.

Estragon: In the meantime let us try to converse calmly, since we are incapable of keeping silent.

Vladimir: You're right, we're inexhaustible.

Estragon: It's so we won't think.

Vladimir: We have that excuse.

Estragon: It's so we won't hear.

Vladimir: We have our reasons.

Estragon: All the dead voices.

Vladimir: They make a noise like wings.

Estragon: Like leaves.

Vladimir: Like sand.

Estragon: Like leaves. [*Silence.*]

Vladimir: They all speak together.

Estragon: Each one to itself. [*Silence.*]

Vladimir: Rather they whisper.

Estragon: They rustle.

Vladimir: They murmur.

Estragon: They rustle. [*Silence.*]

Vladimir: What do they say?

Estragon: They talk about their lives.

Vladimir: To have lived is not enough for them.

Estragon: They have to talk about it.

Vladimir: To be dead is not enough for them.

Estragon: It is not sufficient. [*Silence.*]

Vladimir: They make a noise like feathers.

Estragon: Like leaves.

Vladimir: Like ashes.

Estragon: Like leaves. [*Long silence.*]

Vladimir: Say something!

Estragon: I'm trying [*Long silence*]

Vladimir: [*In anguish*] Say anything at all! (Beckett, 1956, p53-54).

When profound boredom confronted the person with the grim reality of death, s/he was prompted to live in the authentic or inauthentic mode of existence. Vladimir and Estragon's description of waiting for Godot signified that they were unable to live in

either mode of existence. As mentioned previously, the inability to live in either mode of existence in response to boredom resulted in the unpleasant and distressing moods we encountered on an everyday basis.¹⁸³

The narratives of several participants in my study highlighted how their experience of waiting prevented them from living in either an authentic or inauthentic mode of existence. Consequently, the distressing feelings of uneasiness, irritation, frustration, anger, sadness, disappointment, depression, hopelessness, and despair were threaded throughout their accounts. The ongoing nature of the experience of waiting meant the inability to live in either mode of existence continued on a long-term basis for some participants. As a result, these unpleasant and distressing moods developed and intensified over time.

This was highlighted in the follow-up interview with the participants. The participants' accounts illustrated how their distress accelerated while they waited indefinitely for a kidney transplant. They described how their experience of uncertainty, eventually led to disappointment, depression, and finally hopelessness and despair. The participants also indicated that their experience of waiting, described in the theme *Lost Time* ranged from uneasiness and irritation to sheer frustration, anger, and eventually despair.

This intensification of moods was palpable within Beckett's play *Waiting for Godot*. Like the participants in the study, throughout the play Vladimir and Estragon were unable to live in the authentic or inauthentic existence in response to profound boredom. Hence, their experience of distress accelerated to a level of sheer hopelessness and despair. This was emphasised in Act 2, where the characters' discussion about suicide was at a more advanced stage than it had been in Act 1 (Graver, 2004).

Toward the end of Act 1, Estragon had contemplated suicide, and asked Vladimir to remind him to bring a rope tomorrow. However, in Act 2, Estragon actually insisted that they hang themselves and offered his belt to perform the act. Vladimir's increased desperation was also notable, because unlike in Act 1, he agreed with Estragon's proposition to commit suicide. When the two men tested the strength of the belt as a

¹⁸³ See page 125 for the previous discussion on Heidegger's account of the fundamental existential mood of boredom.

suicide instrument, it broke and they fell to the ground. While this scene was humorously articulated within the play, the utter hopelessness and despair experienced by the characters was apparent.

In contrast to Vladimir and Estragon's experience of waiting for Godot, the follow-up interview highlighted that some participants in my study were able to live in the inauthentic mode of existence in response to profound boredom. They described their efforts to re-engage in everyday tasks and activities in world-time. By choosing to live in the inauthentic mode of existence, these participants were able to reconnect the threefold structure of ordinary temporality, and overcome the experience of profound boredom. This subsequently enabled them to overcome the experience of waiting, described in the themes *Lost Time* and *Waiting for a Kidney Transplant*.