University of Alberta

Adjustment Demands through Diagnosis and Treatment of End Stage Renal Disease

By

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Abstract

End Stage Renal Disease (ESRD) is a chronic illness that results when the kidneys are no longer able to function to maintain life. Upon cessation of kidney function, patients must undergo life long medical treatment involving dialysis or transplantation to survive. Patients face an adverse situation as both the disease and treatment are life threatening, and there is no cure. Despite the numerous advancements in treating ESRD, a myriad of stressors affect patients' lives that require significant adjustment. Adjustment is a construct that is not well defined in the literature, or understood from a patient's perspective. For the purpose of this study, adjustment will be explored in terms of adjustment demands patients face as they progress through diagnosis and treatment of ESRD. No research has been found on adjustment demands faced by recipients of kidney transplants in Canada. Additionally, no research has been done in Occupational Therapy and adjustment in patients with ESRD. This was a qualitative study utilizing a phenomenological approach. Study results stress the need for individualized holistic care, education and support.

TABLE OF CONTENTS

LIST OF TABLES

Chapter 1

Introduction:

End Stage Renal Disease (ESRD) is an incurable chronic illness whereby kidney function is insufficient to sustain life (Quinan, 2007). The incidence and prevalence of this illness is startling. Worldwide, 1.8 million people were treated for ESRD in 2004, a 20% rise from 2001 (Knoll, 2008). In 2008, an estimated 36,638 Canadians were living with ESRD, a dramatic increase of 57% from 1999 (Canadian Institute for Health Information, 2010). In 2000, the direct healthcare cost to treat ESRD in Canada was $1.3 billion, an estimated sixteen times more than what was spent on average per person to care for all health conditions (Zelmer, 2007).

Patients with ESRD face a catastrophic and fatal illness as both the disease and treatment are life threatening, and there is no cure. Consequently, psychological distress is highly prevalent among patients (Gilbar et al., 2005). Epidemiologic studies indicate that the rate of psychiatric disorders is substantially higher in patients with ESRD than that observed in other chronic diseases (Christensen et al., 2002).

The ability to adjust to kidney disease and its treatment has become more crucial in the last 25 years as medical, pharmacological and technological advances have dramatically increased the life expectancy of patients (Chowanec and Binik, 1989). Despite these impressive advances, numerous acute and chronic stressors impact patients' lives forcing them to make significant adjustments. Patients experience the continuing threat of death, functional decline, changes in roles and relationships, jeopardized self-concept, economic hardship, and dependency on medical staff and technology (Devins et al., 1997). Changes in patients' marital, familial, occupational and societal contexts are inevitable (Curtin et al, 2005).

In the past two decades copious amounts of research has focused on comparing the quality of life among patients who are receiving different forms of dialysis versus transplantation. The majority of the results indicate that successful renal transplant recipients fair a better quality of life than those receiving dialysis. Dialysis does impose severe restrictions on patients' daily lives which transplantation can alleviate, however, life with a chronic illness and its associated adjustment demands continues.

Literature Review:

The following literature review outlines the causes of ESRD, followed by complications associated with ESRD. Treatment options for ESRD are covered with an emphasis on kidney transplantation. Lastly, a review of the literature on adjustment is summarized.

Kidney Basics:

Typically, a person is born with two kidneys: each kidney is the size of a clenched fist and are located on either side of the spine protected by the lower ribs (Kidney Foundation of Canada). The kidneys have three essential functions. The kidneys remove waste from the blood via urine; regulate the levels of water and minerals needed for optimal health, and produce hormones that control key body functions such as blood pressure, production of red blood cells, and uptake of calcium from the intestine (Kidney Foundation of Canada).

Kidney Disease:

The leading causes of kidney failure as reported by the Kidney Foundation of Canada are diabetes (35%), renal vascular disease including hypertension (19.5%), and glomerulonephritis (11.5%), an inflammation of the filtering units of the kidney. End Stage Renal Disease occurs when the kidneys lose the ability to maintain the volume, composition, and distribution of body fluids essential for well being (Gray, Brogan & Kutner, 1985). The diagnosis of ESRD means the kidneys are permanently damaged, are functioning at less than 10%, and can no longer function to maintain life (Zelmer, 2007).

Complications Associated With ESRD:

There are many complications associated with ESRD that cause undesirable effects. These complications include hypertension, fluid overload, anemia, unsafe mineral levels, changes in nerve function, and skin changes (Kidney Foundation of Canada; The NIH). Healthy kidneys normally produce a hormone that helps to regulate blood pressure called renin. Diseased kidneys often produce abnormal amounts of renin causing hypertension (Kidney Foundation of Canada). This begins a vicious cycle with hypertension causing further damage to the kidneys, causing the kidneys in turn to create more renin, which in turn worsens the hypertension.

Patients with ESRD are often fluid overloaded since the kidneys are not effective in removing excess fluid from the body (The NIH). This overload in fluid results in rapid weight gain, hypertension and edema (Kidney Foundation of Canada). Consequently, patients are asked to adhere to a strict fluid and salt intake regime.

Anemia is a common condition caused by ESRD (Kidney Foundation of Canada; The NIH). Anemia results in patients feeling listless, tired, short of breath and more sensitive to cold. Treatment for anemia includes medications, dietary changes, supplements, and blood transfusions (Kidney Foundation of Canada).

With ESRD, potassium is not effectively removed from the blood, and high potassium levels can cause serious problems with heart conductivity (Kidney Foundation of Canada). Dietary changes are required to limit potassium rich foods (NARP Orientation Manual, 2009).

Besides potassium, the kidneys are responsible for regulating the levels of calcium and phosphate in the blood that is essential for healthy bone metabolism (The NIH). As kidney function declines, phosphate levels rise causing symptoms such as itching, painful and swollen joints, and weakened bones (Kidney Foundation of Canada). Additionally, the kidneys play a vital role in metabolizing vitamin D which controls how well the body absorbs calcium and turns it into bone (The NIH). With damaged kidneys Vitamin D is not processed properly which results in bones losing calcium. Treatment for bone problems involves lifestyle, medication and dietary changes (Kidney Foundation of Canada).

Patients with ESRD may experience changes in nerve function in their legs, feet, arms and hands (Kidney Foundation of Canada). Patients may have restless legs, burning sensation, numbness and tingling: these symptoms are often treated with medications (Kidney Foundation of Canada).

With ESRD, toxins build up not only in the blood, but the skin as well, resulting in dryness, scaling and itching (Kidney Foundation of Canada).

Treatment involves special skin care techniques, dietary changes to control phosphate, special creams and medications (Kidney Foundation of Canada).

Treatment for ESRD:

A mere four decades ago, a diagnosis of ESRD meant near certain death (Christensen et al., 2002). With the advancements in the treatment of ESRD, individuals with kidney disease can live many years despite the severity of their disease (Klang et al., 1996). Thus patients tend to be older, more likely to have diabetes, and suffer from additional co-morbidities (Jassal, Schaubel, & Fenton, 2005).

In order to stay alive, patients with ESRD must begin dialysis or receive a kidney transplant (Christensen et al., 2002). Each treatment poses its own set of challenges that can profoundly impact patients' lives. Due to the shortage of donor organs and transplant rejection rates, dialysis remains the life-sustaining treatment for the large majority of patients (Quinan, 2007). Even with treatment, patients with ESRD endure a poorer than average health status and quality of life (Zelmer, 2007).

Dialysis acts as an artificial kidney (Kidney Foundation of Canada). There are 2 main types of dialysis, hemodialysis and peritoneal dialysis. Hemodialysis is a time consuming, extremely rigid and intrusive medical treatment that involves the use of a dialysis machine to filter and clean the blood. Hemodialysis can be performed in hospital or at home. If performed in hospital, it is normally scheduled three times a week with a session lasting 3-4 hours. A registered nurse is responsible for the set-up and monitoring of the entire treatment. Home hemodialysis involves having a dialysis machine at home, and the patient or caregiver independently managing the entire dialysis routine. According to the Canadian Institute for Health Information (2010), hemodialysis was the most consistently utilized primary modality to treat ESRD in the last decade.

Peritoneal dialysis uses the peritoneum, a membrane that covers the abdominal organs as a filter (Kidney Foundation of Canada). The peritoneal cavity is filled with a glucose-based solution via a permanently implanted abdominal catheter. Through osmosis, excess water and waste pass through the peritoneum into the dialysis fluid. This fluid is then drained from the body and discarded. This process, called an exchange, is repeated 4 to 6 times a day, 7 days a week. An exchange takes approximately forty-five to sixty minutes to complete. Peritoneal dialysis is a versatile treatment that can be performed in any clean environment.

Transplantation involves a kidney from a living or deceased donor being surgically implanted into the lower abdomen (Kidney Foundation of Canada). The single transplanted kidney is able to do the work of two healthy kidneys. Knoll (2008) states that kidney transplantation offers patients with ESRD the greatest potential for increased longevity (Narayanan et al, 2010) and enhanced quality of life (Villeneuve et al., 2007). Walraven et al. (2010), reports that kidney transplant recipients have a 68% lower risk of death compared to patients who are on dialysis that are candidates for transplantation. For the majority of Canadian patients with ESRD, kidney transplantation is the preferred treatment (Canadian Institute for Health Information, 2010). Unfortunately, the need for organs far outweighs the available supply (Kidney Foundation of Canada). The number of patients on the wait list to receive a kidney transplant in Canada has increased by fifteen percent since 1996 (Knoll, 2008). From 1999 to 2008 in Canada, a total of 6,468 deceased donor kidney transplants, and 3,957 living donor kidney transplant surgeries were performed (Canadian Institute for Health Information, 2010).

Implicit Challenges with Kidney Transplantation:

Kidney transplantation frees patients from the limitations and restrictions imposed by dialysis (Starzomski and Hilton, 2000), and offers greater longevity (Villeneuve et al., 2007; Knoll, 2008); however, the physical and emotional consequences of a transplant redefine life of the recipient. A qualitative study completed by Orr et al. (2007), reports long-term psychosocial effects of living with a transplanted kidney. These include feelings of gratitude to the donor, family and the medical team; experiencing the pressure not to let others and themselves down; the necessity of constant vigilance, reduced spontaneity and preoccupation with self-care to maintain the health of the kidney; the urge to increase their knowledge about their condition; the intrusiveness of their medical care; the feeling of being ‘not normal’ and being treated differently from others.

Wait times to receive a deceased donor kidney transplant are not only dependent on the supply of organs, but also on the blood type of the transplant recipient. Wait times range from less than 2 years for blood group AB, 6 months to 2 years for blood group A, and up to 4 years for blood group B and O (NARP Orientation Binder, 2009). According to the Kidney Foundation of Canada, as of December 31, 2007, 71% of the people on the transplant waiting list in Canada were waiting for a kidney.

As recently as 15 years ago, only 40% of kidney transplant patients survived for one year following transplant (Frazier et al., 1995). Survival of transplant recipients has increased over the last 10-15 years largely due to advancements in surgical techniques, improved immunosuppressive medications, and better long-term medical management (Kim et al., 2005). Nevertheless, survival of the kidney transplant recipient remains inferior to that of the general population (Narayanan et al., 2010). The leading causes of death in deceased donor kidney transplant recipients are cardiovascular disease (22%), infection (16%), malignancy (6.8%) and cerebrovascular/hemorrhage (6.3%) (Knoll, 2008). Also, no cure is available to prevent the recurrence of the underlying cause of end stage renal failure (Dobbels et al., 2007).

Potent immunosuppressive medications must be taken every day for the rest of the patient’s life to prevent the body from rejecting the new kidney. Even so, there is always a chance that the body will reject the transplanted organ, and the threat of being forced to resume dialysis is an ever present reality. The incidence of rejection in the first year is 50%, and although the incidence decreases in later years, a risk still remains (Cunningham et al., 1992).

A kidney transplant is not a cure. A transplanted kidney from a deceased donor lasts on average from 10 to 15 years, while a living donor kidney lasts on average from 15 to 20 years (NARP Orientation Manual, 2009). Upon the cessation of kidney function the patient must restart dialysis and the process to receive another transplant.

The required immunosuppressive medications generate many distressing side effects. Use of long-term immunosuppressive drugs affect many body systems and may cause bacterial infections, obesity, heart disease, high cholesterol, hypertension, diabetes, osteoporosis, and skin cancer (Talas and Bayraktar, 2004; Murphy, 2007). One of the main causes of death in transplant recipients who have survived renal transplantation for over 10 years is cancer, and as the period of immunosuppressive medication use is prolonged, the risk for malignancy increases (Talas and Bayraktar, 2004). Villeneuve et al., (2007), found that kidney transplant patients had cancer incidence rates of two and a half times higher than rates observed in the general Canadian population.

Lifestyle changes and health promotion are imperative post transplant. Patients must complete regular blood work and receive ongoing surveillance from the medical team to monitor for infection, malignancies and rejection. Patients must monitor their food intake, weight, blood pressure, and blood sugar. They must be well-informed and diligent in recognizing signs and symptoms of rejection, and seek medical attention immediately. Because the immune system is suppressed, patients must be diligent in following infection control and safe practices to minimize their risk. Alcohol alters the level of anti-rejection medications and causes dehydration that is hard on the kidney. Hence, drinking alcohol is not recommended for patients with a transplanted kidney. Furthermore, to prevent damage to the transplanted kidney, participation in contact leisure activities is not encouraged.

Illness Intrusiveness:

Implicit in many of the stressors imposed by kidney transplantation is the concept of illness intrusiveness. Illness intrusiveness is the degree to which an illness and its associated treatments interfere with normal daily life activities (Binik et al., 1990). Illness induced disruptions to valued activities and interests limit the availability of positive rewarding experiences (Devins et al., 1997). According to Devins et al.(1997), illness intrusiveness influences psychosocial outcomes among people affected by chronic disease through two complimentary mechanisms. First, intrusiveness directly reduces positive experience when the condition interferes with participation in valued activities and interests. Secondly, its affects are indirect due to reduced perception of personal control.

Binik et al. (1990) found that increased perceived intrusiveness of ESRD was significantly related to greater marital role strain, poorer marital adjustment, and decreased individual well-being. Devins et al. (1997) study found that illness intrusiveness not only affects the patient, but also their spouse and the social climate of the family.

Adjustment:

Illness is a multifaceted phenomenon that includes biological, psychological, social, environmental, familial, psychosocial, and psychosexual factors (Kocaman, et al., 2007). Consequently, illness can adversely affect adjustment at many levels. A diagnosis of ESRD entails a variety of chronic recurrent stressors, significant changes in lifestyle, disruption of familial roles and social identity, and threatened personal control (Christensen et al., 2002). Continual adjustment by patients is required to manage their frequently changing circumstances. Changes in roles in the family, work, and social situation create adjustment challenges not only for the patient but for everyone involved (Perkins, 2007).

Adjustment is a process rather than an end state that encompasses physical, mental and social well-being (Starzomski and Hilton, 2000). Adjustment to a chronic illness includes physiological, emotional, behavioral and cognitive aspects. De Ridder et al. (2008), summarized that in order to promote healthy adjustment patients should remain as active as is reasonably possible, acknowledge and express their emotions in a way that allows them to take control of their lives, engage in self-management, and try to focus on potential positive outcomes of their illness. Self-management is characterized by many responsibilities regarding medication use, lifestyle changes, and behavior to prevent long-term complications (De Ridder et al., 2008). When adjustment is achieved, patients are able to value their abilities, acknowledge their limitations, effectively problem solve, and actively participate in all desired aspects of life (Smedema et al., 2009).

A review of the literature on adjustment in ESRD shows that published studies contain arbitrary and inconsistent conceptualizations of adjustment, and that the construct has never been defined (Wright and Kirby, 1999). No direct measures of adjustment exist; therefore, adjustment has been measured indirectly through measures of return to work, depression, social functioning and compliance (Keogh and Feehally, 1999). Unfortunately, studies report conflicting and inconsistent results. Some studies report less depression and improvements in functional status following renal transplantation (Christensen et al., 1991; Gray, Brogan & Kutner, 1985), one study reports mild anxiety and mild depression in kidney transplantation patients even 5 to 9 years post transplant (Simmons et al., 1981), while another study shows no differences in emotional adjustment or quality of life (Devins et al., 1990). No research has been completed on adjustment in kidney transplant recipients within the Canadian healthcare system. Additionally, few if any studies have considered the conceptualizations of patients, partners and/or the healthcare team (Wright and Kirby, 1999).

Literature Review Summary:

The literature emphasizes ESRD as a significant and growing health care challenge. Patients with ESRD suffer from a chronic illness with multiple acute and chronic stressors and there is no cure. This implies a long-term adjustment to a chronic illness and its treatment demands. A review of the literature on adjustment in ESRD shows that the construct has never been clearly defined, and as a result not directly and consistently measured (Wright and Kirby, 1999). Furthermore, limited research has been completed on adjustment in kidney transplant recipients. It is crucial to understand patients' adjustment demands to be able to provide quality care to patients and their families. With this understanding, healthcare professionals will have the knowledge to promote healthy adjustment; thus enabling patients to lead satisfying and productive lives.

Occupational Therapy and ESRD:

Management of kidney disease goes beyond dialysis and transplantation. Patients’ physical, mental, emotional, social and spiritual health and well-being can be improved with Occupational Therapy. ESRD and treatment dramatically disrupts patients’ lives. Patients are faced with a multitude of stressors with their changing health status and treatment requirements. Demanding in and of themselves, these stressors impose significant interruptions to everyday life. To provide optimal care it is imperative to gain an understanding of the impact of ESRD on patients' lives. Occupational Therapists have unique skills and a knowledge base to assess the impact of illness on everyday functioning. Patients are viewed holistically, and there are no preconceived biases about how the patient should feel or act. Rather, each patient's unique life context and experiences are understood. This allows for an understanding of the demands patients face, as well as recognizing the patient's responses to the challenges that ESRD and treatment imposes. Patients are not considered in isolation from their social context. Social support and marital context are crucial elements to facilitate adjustment to kidney disease and treatment (Chowanec and Binik, 1989). It is necessary to work not only with the patient, but the family as well, as they too may be experiencing detrimental effects from the disease and treatment. With Occupational Therapy intervention, patients are integrated back into family and community life. No research studies have been completed in Occupational Therapy to understand the adjustment demands of patients with ESRD.

The purpose of this study is to understand the adjustment demands patients face as they progress through diagnosis and treatment of ESRD. Research on the adjustment demands faced by recipients of kidney transplants within the Canadian healthcare system is lacking, and the literature review on adjustment in ESRD shows that the construct is not clearly defined (Wright and Kirby, 1999). Understanding adjustment from a patient's perspective, as they progress through the stages of kidney disease and treatment will result in enhanced knowledge and insight. This information can be utilized for early detection of adjustment issues, and provision of timely intervention. Furthermore, research findings can be used to develop educational materials and support programs to facilitate positive adjustment to a life-long illness.

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Chapter 2

Introduction:

End Stage Renal Disease (ESRD) is an incurable chronic illness whereby kidney function is insufficient to sustain life (Quinan, 2007). The incidence and prevalence of this illness is startling. Worldwide, 1.8 million people were treated for ESRD in 2004, a 20% rise from 2001 (Knoll, 2008). In 2008, an estimated 36,638 Canadians were living with ESRD, a dramatic increase of 57% from 1999 (Canadian Institute for Health Information, 2010). In 2000, the direct healthcare cost to treat ESRD in Canada was $1.3 billion, an estimated sixteen times more than what was spent on average per person to care for all health conditions (Zelmer, 2007).

Upon the cessation of kidney function, patients must undergo life-long medical treatment involving dialysis or transplantation to survive. Patients with ESRD face a catastrophic and fatal illness as both the disease and treatment are life threatening, and there is no cure. Consequently, psychological distress is highly prevalent among patients (Gilbar et al., 2005). Epidemiologic studies indicate that the rate of psychiatric disorders is substantially higher in patients with ESRD than that observed in other chronic diseases (Christensen et al., 2002).

The ability to adjust to kidney disease and its treatment has become more crucial in the last 25 years as medical, pharmacological and technological advances have dramatically increased the life expectancy of patients (Chowanec and Binik, 1989). Despite these impressive advances, numerous acute and chronic stressors impact patients' lives forcing them to make significant adjustments to their way of life. Patients experience the continuing threat of death, functional decline, changes in roles and relationships, jeopardized self-concept, economic hardship, and dependency on medical staff and technology (Devins et al., 1997). Changes in patients' marital, familial, occupational and societal contexts are inevitable (Curtin et al, 2005).

In the past two decades, a copious amount of research has focused on comparing the quality of life among patients who are receiving different forms of dialysis versus transplantation. The majority of the results indicate that successful renal transplant recipients fair a better quality of life than those receiving dialysis. Dialysis imposes severe restrictions on patients' daily lives which transplantation can alleviate (Wainwright et al., 1999), however, life with a chronic illness and its associated adjustment demands on the patient continues.

Patients and clinicians need to be aware of the adjustment demands required after transplantation. A review of the literature on adjustment in ESRD shows that the construct is ill defined (Wright and Kirby, 1999). Furthermore, limited research has been completed on the adjustment demands faced by recipients of kidney transplants, and within the Canadian healthcare system.

Literature Review:

Kidney Disease:

Kidney disease does not discriminate, and can strike anyone at any age (Kidney Foundation of Canada). The leading causes of kidney failure as reported by the Kidney Foundation of Canada are diabetes (35%), renal vascular disease including hypertension (19.5%), and glomerulonephritis (11.5%), an inflammation of the filtering units of the kidney. End Stage Renal Disease (ESRD) occurs when the kidneys lose the capability of maintaining the volume, composition, and distribution of body fluids essential for well being (Gray, Brogan & Kutner, 1985). The diagnosis of ESRD means the kidneys are permanently damaged, are functioning at less than 10%, and are no longer able to function to maintain life (Zelmer, 2007).

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ESRD, individuals with kidney disease can live many years despite the severity of their disease (Klang et al., 1996). As such, patients tend to be older, more likely to have diabetes, and suffer from additional co-morbidities (Jassal, Schaubel, & Fenton, 2005). In order to stay alive, patients with ESRD must begin dialysis or receive a kidney transplant. These treatments are not without difficulties and complications, and can profoundly impact every aspect of a patient's life. Due to the shortage of donor organs and significant transplant rejection rates, dialysis remains the life-sustaining treatment for the large majority of patients (Quinan, 2007). Even with treatment, patients with ESRD endure a poorer than average health status and quality of life (Zelmer, 2007).

Treatment for ESRD:

Dialysis acts as an artificial kidney (Kidney Foundation of Canada). There are 2 main types of dialysis, hemodialysis and peritoneal dialysis. Hemodialysis is a time consuming, extremely rigid, and intrusive medical treatment that involves the use of a dialysis machine to filter and clean the blood. Hemodialysis can be performed in hospital or at home. If performed in hospital, it is normally scheduled three times a week with a session lasting 3-4 hours. A registered nurse is responsible for the set-up and monitoring of the entire treatment. Home hemodialysis involves having a dialysis machine at home, and the patient or caregiver independently managing the entire dialysis routine. Home dialysis is usually performed daily during sleeping hours. According to the Canadian Institute for Health Information (2010), hemodialysis was the most consistently utilized primary modality to treat ESRD in the last decade.

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Kidney transplantation frees patients from the limitations and restrictions imposed by dialysis (Starzomski and Hilton, 2000), and offers greater longevity (Villeneuve et al., 2007; Knoll, 2008); however, the physical and emotional consequences of a transplant restructure and redefine life of the recipient. A qualitative study completed by Orr et al. (2007), reports long-term psychosocial effects of living with a transplanted kidney. These include feelings of gratitude to the donor, family and the medical team; experiencing the pressure not to let others and themselves down; the necessity of constant vigilance, reduced spontaneity and preoccupation with self-care to maintain the health of the kidney; the urge to increase their knowledge about their condition; the intrusiveness of their medical care; the feeling of being ‘not normal’ and being treated differently from others.

Wait times to receive a deceased donor kidney transplant are dependent on the supply of organs, and on the blood type of the transplant recipient. Wait times range from less than 2 years for blood group AB, 6 months to 2 years for blood group A, and up to 4 years for blood group B and O (NARP Orientation Binder, 2009). According to the Kidney Foundation of Canada, as of December 31, 2007, 71% of the people on the transplant waiting list in Canada were waiting for a kidney.

As recently as 15 years ago, only 40% of kidney transplant patients survived for one year following transplant (Frazier et al., 1995). Survival of transplant recipients has increased over the last 10-15 years largely due to advancements in surgical techniques, improved immunosuppressive medications, and better long-term medical management (Kim et al., 2005). Nevertheless, survival of the kidney transplant recipient remains inferior to that of the general population (Narayanan et al., 2010). The leading causes of death in deceased donor kidney transplant recipients are cardiovascular disease (22%), infection (16%), malignancy (6.8%) and cerebrovascular/hemorrhage (6.3%) (Knoll, 2008). Also, no cure is available to prevent the recurrence of the underlying cause of end stage renal failure (Dobbels et al., 2007).

Potent immunosuppressive medications must be taken every day, for the rest of the patient's life to prevent the body from rejecting the new kidney. Even so, there is always a chance that the body will reject the transplanted organ, and the threat of being forced to resume dialysis is an ever present reality. According to Morrissey et al.,(2007), kidney allograft survival rate exceeds 90%, and within one year rejection rates are under ten percent.

A kidney transplant is not a cure. A transplanted kidney from a deceased donor lasts on average from 10 to 15 years, while a living donor kidney lasts on average from 15 to 20 years (NARP Orientation Manual). Upon the cessation of kidney function, the patient must restart both dialysis, and the process to receive another transplant.

The required immunosuppressive medications generate many distressing side effects. Use of long-term immunosuppressive drugs affect many body systems, and may cause bacterial infections, obesity, heart disease, high cholesterol, hypertension, diabetes, osteoporosis, and skin cancer (Talas and Bayraktar, 2004; Murphy, 2007). One of the main causes of death in transplant recipients who have survived renal transplantation for over 10 years is cancer, and as the period of immunosuppressive medication use is prolonged, the risk for malignancy increases (Talas and Bayraktar, 2004). Villeneuve et al., (2007), found that kidney transplant patients had cancer incidence rates of two and a half times higher than rates observed in the Canadian population.

Lifestyle changes and health promotion are imperative post transplant. Patients must complete regular blood work, and receive ongoing surveillance from the medical team to monitor for infection, malignancies and rejection. Patients must monitor their food intake, weight, blood pressure, and blood sugar. They must be well informed and diligent with recognizing signs and symptoms of rejection, and seek medical attention immediately. Because the immune system is suppressed, patients must be diligent in following infection control and safe practices to minimize their risk. Patients must monitor, and ideally avoid alcohol consumption. Alcohol not only alters the level of anti-rejection medications, but also causes dehydration which is taxing on the kidney. Furthermore, to prevent injury to the transplanted kidney, participation in contact leisure activities is not encouraged.

Adjustment:

Illness is a multifaceted phenomenon that includes biological, psychological, social, environmental, familial, psychosocial, and psychosexual factors (Kocaman, et al., 2007). Consequently, illness can adversely affect adjustment at many levels. A diagnosis of ESRD entails a variety of chronic recurrent stressors, significant changes in lifestyle, disruption of familial roles and social identity, and threatened personal control (Christensen et al., 2002). Continual adjustment by patients is required to manage their frequently changing circumstances. Changes in roles in the family, work, and social situation create adjustment challenges not only for the patient, but for everyone involved (Perkins, 2007).

Adjustment is a process rather than an end state that encompasses physical, mental and social well-being (Starzomski and Hilton, 2000). Adjustment to a chronic illness includes physiological, emotional, behavioral and cognitive aspects. De Ridder et al. (2008) summarized that in order to promote healthy adjustment, patients should remain as active as is reasonably possible, acknowledge and express their emotions in a way that allows them to take control of their lives, engage in self-management, and try to focus on potential positive outcomes of their illness. Self-management is characterized by many responsibilities regarding medication use, lifestyle changes, and behavior to prevent long-term complications (De Ridder et al., 2008). When adjustment is achieved, patients are able to value their abilities, acknowledge their limitations, effectively problem solve, and actively participate in all desired aspects of life (Smedema et al., 2009).

A review of the literature on adjustment in ESRD shows that published studies contain arbitrary and inconsistent conceptualizations of adjustment, and that the construct has never been defined (Wright and Kirby 1999). No direct measures of adjustment exist. As a result, adjustment has been measured indirectly through measures of return to work, depression, social functioning and compliance (Keogh and Feehally, 1999). Unfortunately studies report conflicting and inconsistent results. Some studies report less depression and improvements in functional status following renal transplantation (Christensen et al., 1991; Gray, Brogan & Kutner, 1985), one study reports mild anxiety and mild depression in kidney transplantation patients even 5 to 9 years post transplant (Simmons et al., 1981), while another study shows no differences in emotional adjustment or quality of life (Devins et al., 1990). No research has been completed on adjustment in kidney transplant recipients within the Canadian healthcare system. Additionally few if any studies have considered the conceptualizations of patients, partners and/or the healthcare team (Wright and Kirby 1999).

The purpose of this study was to explore patients' adjustment demands as they progress through the stages of ESRD and treatment. Qualitative research methods were used to explore adjustment demands in patients who have received, and patients who are currently on the wait list for a kidney transplant. Including two groups of patients in the sample allowed for interesting comparison of adjustment demands. An emphasis was placed on the real and perceived adjustment demands of patients post kidney transplant. The variety of responses added a rich perspective to demands patients face throughout their disease and treatment process.

Results will generate research in the area of adjustment to facilitate evidence based practice. It is imperative for the healthcare team to understand patients' adjustment demands to be able to provide excellent care. With this understanding, healthcare professionals have the knowledge to promote healthy adjustment; thus enabling patients to lead satisfying and productive lives.

Research Methods:

Study Design:

This qualitative study utilized a phenomenological approach. This approach allows for an understanding of a given phenomenon within its own context, focusing on the way people interpret their experiences within their own world (Wicks and Whiteford, 2006). The qualitative approach provided an emic or insider’s perspective and experience (Wicks and Whiteford, 2006), which is imperative to understanding the adjustment demands of living with a chronic disease. The study design allowed for an exploration and description of adjustment demand purely from the participants' perspective, without imposing preconceptions.

Study Participants:

Participants were patients being followed by the Northern Alberta Renal Program (NARP) at the University of Alberta Hospital. Two separate groups of participants were selected; those who have had a kidney transplant, and those who are awaiting a kidney transplant. The advantage of using participants from one facility is that they were all provided with similar care. The following was the inclusion criteria for the post kidney transplant participants.

- Received a kidney transplant at the University of Alberta Hospital
- Currently being followed by the NARP
- Received a kidney transplant at a minimum of age 18
- Recipient of a kidney transplant for a minimum of one year, as within one year, the medical management of the transplant is stabilized
- Currently has a functioning kidney transplant
- Attended a program of Occupational Therapy
- Able to speak and comprehend English so able to participate in the interview
- Resides in Edmonton or surrounding vicinity

The inclusion criteria for pre-transplant participants were the same, with the exception of criteria specifically related to kidney transplantation. The pre-transplant participants were also at least 18 years of age and currently receiving dialysis treatment.

Sample Size:

The sample consisted of 18 participants: twelve participants in the post-kidney transplant group, and six participants in the pre-kidney transplant group. Having the 2 groups of participants allowed for not only an interesting comparison, but also an understanding of the adjustment demands throughout the stages of ESRD. The sample size for this study follows the general trend for a phenomenological study where information is collected using in-depth interviews with as many as ten individuals (Creswell, 2007). Interviews provided rich thick description of adjustment demands faced by the participants. Interviews were discontinued as data saturation had occurred with both groups, as no new major or relevant data was emerging.

Sample:

The gender distribution of participants was 61% male and 39% female. The mean age of the participants was 50.33 years with a standard deviation of 13.52 years. The age range was from 25–71 years of age. The mean age of the pre-transplant group was 39, compared to 56 in the post-transplant participants.

Seventy-two percent of the participants were married. In regards to education level, 33% had a high school education and 61% had completed post secondary education. A minority (22%), of the participants were employed at the time of the study, and 55% of the participants were unemployed. The entire pre-transplant group was unemployed versus 42% of the post-transplant group.

Household income for 56% of the participants was over $50,000/year. In the post-transplant group 33% of the participants had a household income over $100,000 compared to 17% of the pre-transplant group. The two main causes of kidney disease for study participants were diabetes and polycystic kidney disease. In the pre-transplant group diabetes was the cause of kidney failure for 67% of the participants. The post-transplant participants had varied diagnosis with polycystic kidney disease accounting for 33% of the cases. The most common treatment for kidney disease was conventional hemodialysis in hospital for 61% of the participants. Seventy-eight percent of the participants had completed dialysis treatment for at least two years. In the twelve post-kidney transplant participants, 75% had a deceased donor kidney transplant.

Table 2-1 Distribution of demographic and medical variables in pre-transplant sample of 6 participants

<table>
<tr><td colspan="12">Gender:</td></tr>
<tr><td colspan="6">Male</td><td colspan="6">Female:</td></tr>
<tr><td colspan="6">n 4</td><td colspan="6">n 2</td></tr>
<tr><td colspan="6">% 67</td><td colspan="6">% 33</td></tr>
<tr><td colspan="6">Age (years):</td><td colspan="6"></td></tr>
<tr><td colspan="12">M 38.67</td></tr>
<tr><td colspan="12">SD 8.31</td></tr>
<tr><td colspan="12">Marital Status:</td></tr>
<tr><td colspan="6">Single</td><td colspan="6">Married</td></tr>
<tr><td colspan="6">n 2</td><td colspan="6">n 4</td></tr>
<tr><td colspan="6">% 33</td><td colspan="6">% 67</td></tr>
<tr><td colspan="12">Education:</td></tr>
<tr><td colspan="6">High School</td><td colspan="6">Post Secondary</td></tr>
<tr><td colspan="6">n 3</td><td colspan="6">n 3</td></tr>
<tr><td colspan="6">% 50</td><td colspan="6">% 50</td></tr>
<tr><td colspan="12">Employment Status:</td></tr>
<tr><td colspan="6">Unemployed Receiving AISH</td><td colspan="6">Unemployed Receiving Disability</td></tr>
<tr><td colspan="6">n 3</td><td colspan="6">n 3</td></tr>
<tr><td colspan="6">% 50</td><td colspan="6">% 50</td></tr>
<tr><td colspan="12">Household Income (per annum):</td></tr>
<tr><td colspan="3">Under $19,999</td><td colspan="3">$20,000-$49,999</td><td colspan="3">$50,000-$99,999</td><td colspan="3">$100,000 and Over</td></tr>
<tr><td colspan="3">n 1</td><td colspan="3">n 2</td><td colspan="3">n 2</td><td colspan="3">n 1</td></tr>
<tr><td colspan="3">% 17</td><td colspan="3">% 33</td><td colspan="3">% 33</td><td colspan="3">% 17</td></tr>
<tr><td colspan="12">Cause of Kidney Disease:</td></tr>
<tr><td colspan="4">Diabetes</td><td colspan="4">Polycystic Kidney Disease</td><td colspan="4">Unknown</td></tr>
<tr><td colspan="4">n 4</td><td colspan="4">n 1</td><td colspan="4">n 1</td></tr>
<tr><td colspan="4">% 67</td><td colspan="4">% 17</td><td colspan="4">% 17</td></tr>
<tr><td colspan="12">Current Dialysis Treatment:</td></tr>
<tr><td colspan="6">Hemodialysis</td><td colspan="6">Peritoneal Dialysis</td></tr>
<tr><td colspan="6">n 5</td><td colspan="6">n 1</td></tr>
<tr><td colspan="6">% 83</td><td colspan="6">% 17</td></tr>
<tr><td colspan="12">Length of Time on Dialysis:</td></tr>
<tr><td colspan="4">12 Months or Less</td><td colspan="4">20-36 Months</td><td colspan="4">37 Months and Greater</td></tr>
<tr><td colspan="4">n 2</td><td colspan="4">n 3</td><td colspan="4">n 1</td></tr>
<tr><td colspan="4">% 33</td><td colspan="4">% 50</td><td colspan="4">% 17</td></tr>
</table>

Table 2-2 Distribution of demographic and medical variables in post-transplant sample of 12 participants

Gender:

Male	Female
n 7	n 5
% 58	% 42

Age (years):

M 56.17
SD 11.82

Marital Status:

Single	Married
n 3	n 9
% 25	% 75

Level of Education:

High School	Post Secondary	No Comment
n 3	n 8	n 1
% 25	% 67	% 8

Employment Status:

Unemployed Receiving AISH	Unemployed Receiving Disability	Employed	Retired
n 2	n 3	n 3	n 4
% 17	% 25	% 25	% 33

Household Income (per annum):

Under $19,999	$20,000-$49,999	$50,000-$99,999	$100,000 and Over	No Comment
n 2	n 2	n 3	n 4	n 1
% 17	% 17	% 25	% 33	% 8

Cause of Kidney Disease:

Polycystic Kidney Disease	Diabetes	IgA Nephropathy	Cancer	Reflux Nephropathy	Alport's Syndrome	Lithium Toxicity/E. Coli
n 4	n 3	n 1	n 1	n 1	n 1	n 1
% 33	% 25	% 8	% 8	% 8	% 8	% 8

Type of Dialysis Treatment:

Hemodialysis and Peritoneal Dialysis	Hemodialysis	Peritoneal Dialysis	No Dialysis Treatment
n 3	n 6	n 1	n 2
% 25	% 75	% 8	% 17

Time on Dialysis Prior To Transplant:

No Dialysis	12 Months or Less	24-36 Months	40-48 Months	60-96 Months
n 2	n 2	n 6	n 5	n 3
% 17	% 17	% 50	% 42	% 25

Type of Kidney Transplant:

Deceased Donor	Living Donor
n 9	n 3
% 75	% 25

Diabetic Status:

Diabetic	Non-Diabetic
n 3	n 9
% 25	% 75

Time Living With Kidney Transplant:

12-24 Months	25-36 Months	49-60 Months	110 months and Greater
n 3	n 5	n 1	n 3
% 25	% 42	% 8	% 25

Table 2-3: Distribution of demographic and medical variables in sample of 18 participants

Gender:	
Male	Female
n 11	n 7
% 61	% 39

Age (years):
M 50.33
SD 13.52

Marital Status:	
Single	Married
n 5	n 13
% 28	% 72

Education:			
High School	Post Secondary (Technical)	Post Secondary (University)	No Comment
n 6	n 5	n 6	n 1
% 33	% 28	% 33	% 6

Employment Status:			
Unemployed Receiving AISH	Unemployed Receiving Disability	Employed	Retired
n 4	n 6	n 4	n 4
% 22	% 33	% 22	% 22

Household Income (per annum):				
Under $19,999	$20,000-$49,999	$50,000-$99,999	$100,000 and Over	No Comment
n 3	n 4	n 5	n 5	n 1
% 17	% 22	% 28	% 28	% 6

Cause of Kidney Disease:							
Diabetes	Polycystic Kidney Disease	IgA Nephropathy	Reflux Nephropathy	Alport's Syndrome	Cancer	Lithium Toxicity /E. Coli	Unknown Cause
n 6	n 5	n 1	n 1	n 1	n 1	n 1	n 1
% 33	% 28	% 6	% 6	% 6	% 6	% 6	% 6

Type of Dialysis Treatment:				
HD	HD and PD	PD	HD and Home HD	No Dialysis
n 11	n 3	n 1	n 1	n 2
% 61	% 17	% 6	% 6	% 11

Time on Dialysis:				
No Dialysis	12 Months or Less	24-36 Months	40-48 Months	60-96 Months
n 2	n 2	n 6	n 5	n 3
% 11	% 11	% 33	% 28	% 17

Type of Kidney Transplant: (n=12)	
Deceased Donor	Living Donor
n 9	n 3
% 75	% 25

Diabetic Status:	
Diabetic	Non-Diabetic
n 7	n 11
% 39	% 61

HD-Hemodialysis PD-Peritoneal Dialysis

Data Collection:

All patients who fit the inclusion criteria since 2001, when Occupational Therapy services were included on the Northern Alberta Renal Program (NARP), were contacted by mail to request their participation in the study. The mail out included an introductory letter describing the purpose of the study. It also informed potential participants that they would be receiving a phone call to determine their interest in participating in the study, and to schedule an interview. The primary investigator completed one-to-one semi-structured interviews to understand participants experience with kidney disease, and their meaning/views on adjustment. Interviews ranged in time from 20-75 minutes. All interviews were digitally recorded and transcribed verbatim for analyses. Prior to starting the interview, all participants were provided with a demographic data sheet to complete. At the end of the interview, participants were provided with a list of community support numbers should any distress arise from partaking in the interview. A semi-structured interview guide was devised, and consistent with the qualitative method, questions were not rigidly adhered to allow for interesting points raised by the participant to be followed up in more detail. The following open-ended questions are examples of prompts used to facilitate discussion.

- Can you tell me about your experience with kidney disease/transplantation?
- How do you feel you have adjusted to living with kidney disease/transplantation?
- What factors do you consider important when considering adjustment?
- What do you consider to be healthy adjustment?
- How do you perceive adjustment to be once you receive your transplant?
- Tell me about how you have adjusted as you progressed through the stages of kidney disease?
- What helped you adjust to kidney disease/transplantation?
- What obstacles are there to adjusting to kidney disease/transplantation?

Data Analysis:

Participants' responses were analyzed inductively using thematic analysis (Creswell, 2007). The method of analysis utilized three phases to interpret the data that followed a process based on a fourteen step method described by Burnard (1991). The three phases included: 1) filtering and categorizing the data, 2) condensing, organizing and integrating the data, and

3) understanding and meaning. Phase one resulted in the elimination of information not related to the study, and the initial development of categories. The analysis in phase two created the final categories that had emerged from the interviews. Lastly, phase three allowed for the further refinement of categories and themes by reconnecting with the study participants. Categories and themes were also linked and compared to previous research on adjustment.

Sample demographic data was analyzed using descriptive statistics. Demographic characteristics were classified according to mean, standard deviation, percentage and range.

To ensure the trustworthiness and credibility of the study, and to minimize the influence of researcher's interpretations or alterations of participants lived experience, several strategies were utilized. Creswell (2007), suggests eight procedures for addressing the trustworthiness of qualitative findings, and recommends utilizing at least two strategies in any given study. Strategies used included field notes, personal reflexivity, memos, member checks, and partial saturation.

The use of field notes ensured that important information was not lost in the data analysis process, and also provided the researcher with useful examples and direct quotations that may be important to the results of the study (McReynolds et al., 2001).

Researcher bias was addressed using personal reflexivity during the data collection and analysis process through memos. Memos are a method used throughout the research process to address and record the researcher's personal biases, assumptions and feelings (McReynolds et al., 2001).

Credibility was addressed by using member checks. Reconnecting with participants after the analysis of the interviews allowed for verification of the accuracy of responses, and researcher's interpretations.

A constant comparison method was used to achieve partial saturation. This method involved comparing each new interview to the previous interview(s). This process continued throughout the data collection phase until the point at which no new themes or categories emerged.

Ethical Considerations:

Patients were sent a letter indicating the purpose of the study was to examine adjustment post kidney transplant. The letter outlined that participation is voluntary, confidential and anonymous, and will not impact the care they receive from the NARP. Patients were advised that results of the study will be used to develop programs and resources for NARP patients. The project was reviewed and passed by the Ethics committee that governs both the University of Alberta, and University of Alberta Hospital. All participants were provided with a handout of community support numbers should any distress arise from participating in the study. Data was analyzed and stored at the University of Alberta hospital in a secure office, and filed in a locked cabinet. No identifying information was present on the data collected. All information will be destroyed in five years

Results:

Pre Transplant Data Analysis:

In the pre-transplant group, adjustment demands were analyzed in three stages including diagnosis of kidney disease, treatment with dialysis, and perceived adjustment demands during transplantation. Strategies participants employed during each stage to manage adjustment demands was also examined.

Diagnosis:

Participants' reaction to diagnosis was emotional. Responses to diagnosis included "total shock", "like there was a death in the family", "you feel like you are a victim", "got depressed", and "pretty scary because I didn't know what the future held."

Dialysis:

Four main adjustment demands emerged when participants described their journey from diagnosis to treatment of kidney failure. These include fatigue, mental health concerns, uncertain future, and fluid and dietary restrictions.

Fatigue:

All participants in the pre-transplant group described the detrimental effects of fatigue on occupational performance. This fatigue was described as “no energy”, “warn down”, and “tired all the time”. Fatigue resulted in an inability to participate in work and leisure activities. Female participants were additionally distressed by the incapability to manage homemaking tasks. A female participant described the anguish of having to rely on her husband to be her caregiver, as prior to being struck by kidney disease she was a strong and independent woman.

Mental Health Challenges:

Majority of the pre-transplant participants described mood changes including depression, irritability, frustration and annoyance. Participants expressed hurt when family, friends and co-workers did not believe they were sick. A participant described her co-workers saying, “you look fine what do you mean you are sick.” One participant stated she “felt embarrassed, like there was something wrong with me, and I didn't want to tell anybody." A majority of the pre-transplant group had initiated counseling and medication for depression upon the diagnosis/treatment of kidney disease.

Uncertainty about the Future:

A shared theme was the challenge of adjusting to an unclear future. Specific concerns voiced included, the time frame until having to initiate dialysis, how their health will affect their ability to participate in life, and the wait time to receive a transplant. As one participant explained, "My life used to be perfect. I was happily married, had a great job and I had plans to travel. All this has now come on hold."

Fluid and Dietary Restrictions:

All participants described how much better they felt after initiating dialysis. Equally there was a validation as to the extent of their disease. As one participant explained, "I was really sick, it wasn't in my head." Despite feeling better with dialysis treatment, all participants described the fluid and dietary restrictions as a challenge to adjustment.

Adjusting to Kidney Disease and Treatment:

Three themes were uncovered when participants described what assisted them to adjust to kidney disease and dialysis. These include social support, knowledge, and cognitive-based strategies. Majority of participants described the importance of support from their partner, family and friends to help adjust to diagnosis and treatment of kidney disease.

A vast number of participants stressed the need to be knowledgeable about the disease process and treatment to facilitate adjustment. Participants commented on the importance of listening to the advice and knowledge provided by the healthcare team. Participants stressed the importance of asking questions and being informed of their health and options for treatment.

All participants described utilizing cognitive strategies to adjust to dialysis. One participant described dialysis as not something she needed to survive, but rather as “me time.” She described reading, watching TV, journaling, or catching up on her sleep. Similarly, other participants described “keeping their mind busy” and “distracted.” Other participants explained dialysis as something that had to endure in order to stay alive.

Transplantation:

The pre-transplant group was enthusiastic about the advantages of transplantation, and generally focused on these during the interview. A recurrent theme was feeling better which meant leading a “richer and fuller life,” being able to go back to work, complete daily activities and travel. One participant described having a transplant meant “...to aspire to be what your life used to be…I’ll get a large part of my life back where I can just go.” Also, a commonly occurring theme was that being off dialysis meant lifting of dietary restrictions.

The entire pre-transplant group referred to the side effects of the anti-rejection medications as a negative. Only one participant mentioned the risk of rejection. One participant explained “I have been to the transplant teaching class, and understand the positives and negatives of the transplant, but I still look at it through rose colored glasses.” The common mode of adjustment to waiting for a transplant was “to take one day at a time,” “keep active,” and “whatever happens, happens.”

Post Transplant Analysis:

In the post-transplant group, adjustment demands were examined during the diagnosis of kidney disease, treatment with dialysis, and transplantation phase. Strategies participants utilized during each phase to deal with adjustment demands were also explored.

Diagnosis:

The response to diagnosis included a spectrum of emotions. Participants described feelings of acceptance, shock, anger, anxiety, devastation, uncertainty, fear, disbelief, and relief. One end of the spectrum included participants who accepted the diagnosis, stating, “you can’t get into that self-pity stuff.” Another participant explained, “…because I have a mental health issue, primarily depression-I was able to accept the diagnosis because it didn't seem very high in comparison to being extremely depressed." On the other end of the spectrum were those participants who were very unsettled, describing the diagnosis as "…a death sentence", and disbelief "bullshit this ain't going to happen to me" and "everybody was wrong." Still other participants described being diagnosed as a relief because this led to the initiation of dialysis and feeling better.

Dialysis:

Participants described reduced energy, inability to travel, dietary restrictions, and financial strain as the most common barriers to adjustment while on dialysis. All participants described feelings of weakness and fatigue that made performing daily activities a challenge, and sometimes impossible. Majority of the post-transplant described how dialysis limited their ability to travel due to dialysis schedule, and also the inconvenience of taking supplies. All participants mentioned the dietary and fluid restriction while on dialysis as an adjustment demand. Lastly, financial strain was also common due to refraining or minimizing worked hours, and difficulty receiving disability pay.

Adjusting to Dialysis:

The post-transplant group described acceptance, hope, healthy living strategies, and support network as crucial in assisting with adjusting to dialysis. Acceptance of the diagnosis of the disease process was continually stated as necessary in order to adjust. Some participants described acceptance from a philosophical and religious perspective. For example, “totally resign yourself to the program or life that you are going to have without your kidneys functioning…resignation…accept that this is your fate.” Another participant described, “…accept the reality of what I was going through…knew that I would have a good life.” Another patient described a more practical perspective by explaining, “it is there, it is done, yelling and screaming won’t do anything.” Participants explained, “never thought much about it-just something I had to do”, “I was not stressed out or worried”, “I just got used to it”, and “what helped me was not treating it (dialysis) as anything special.” Other participants described hope of receiving a transplant as key to their adjustment. Healthy living strategies such as exercising and eating right were also stated as important. Finally support from a partner, co-workers and the multidisciplinary healthcare team was identified as significant.

Transplantation:

Three common themes that emerged as barriers to adjustment after transplantation included side effect of medications, risk of rejection and expectations. A majority of participants stated side effects of medication as a major challenge to adjustment. Medication side effects reported as most disturbing were mood changes, tremors, gastrointestinal issues, and body changes such as weight gain, hair loss and acne. When describing rejection risk the post-transplant group was divided as to those who feared rejection, and those who saw rejection as part of the natural cycle of living with kidney disease. Another challenge to adjustment included expectations. One participant who experienced multiple complications after surgery stated "(transplant) didn't live up to my standards. I did not anticipate any problems." Another participant explained, "I think I have been spending a lot of time adjusting to things that have happened to me since the transplant, rather than the transplant itself." Other participants mentioned the high expectations they felt after the transplant. With this "new lease on life" the expectation was that they were "fine" no longer had a "disability" and should be able to restart life.

As for positive adjustments that occurred after transplant, common themes were health had improved, more energy to complete daily activities including work and leisure activities, increased flexibility with diet, and the freedom to travel.

Adjusting To Transplant:

Four common themes emerged when participants described the process of adjusting to transplantation. These include positive thinking, a support network, healthy living, and education. Positivity was stressed as being crucial. Common statements were, “believe you are going to get through it because you will” “look at the future it will be better” and “take it all in good humor.” Having a support network was stated as very important to assist with adjusting to kidney disease and treatment. A partner, friends, family, the multidisciplinary team, and other transplant recipients were all mentioned as supports. The importance of being healthy and taking care of oneself was also stressed. This included eating a balanced diet, exercising, and focusing on mental health and wellness. Lastly knowledge and education was stressed. This included education on the disease process so as to make informed decisions; educating family and friends on the disease process; and educating yourself on the disease process to understand what is happening to you.

Discussion:

Both the pre and post transplant participants described being diagnosed with kidney disease as quite emotional. The pre-transplant group responses were tragic and fueled with negative emotions. The post-transplant group replies however comprised a spectrum of emotions. This may be related to the post-transplant group having more time to accept the diagnosis and experience living with kidney disease. As well, more time had elapsed since being diagnosed with kidney disease, so the recall of emotions may be skewed. One-third of the post-transplant group also consisted of participants with polycystic kidney disease, a genetic condition that is screened for in early teen/adulthood. It is likely that participants had experience with a family member who lived with kidney disease and treatment. All of these factors could result in greater acceptance of the diagnosis.

The common barriers to adjustment during dialysis treatment stated by both groups were fatigue and dietary restrictions. Lindqvist et al. (2000), used quantitative assessment methods to identify stressors with participants on dialysis, and found the most frequent stressors to be fluid and food restrictions, muscle cramps, cramps during dialysis, itchiness, fatigue, physical weakness, variations in health, activity restrictions, frequent hospitalizations, decrease in social contacts, and uncertainty about the future. Interestingly, in the study by Lindqvist et al. (2000), many of the stressors were related to physiological changes related to dialysis. Physiological changes were not mentioned by current study participants. The difference in reporting may be due to quantitative as opposed to qualitative methods utilized.

Fatigue was regarded by study participants as a key barrier to adjustment that had a major negative impact on ability to perform everyday living tasks. A review of research with patients with ESRD shows that fatigue is a universal symptom. Lee et al. (2007) reported that nearly half of all hemodialysis patients experience a certain degree of fatigue and lack of energy. Another study found that up to 82% of hemodialysis patients suffered from fatigue (Merkus et al., 1999). No interdisciplinary definition, or common mechanism for classifying fatigue exists (Lee et al., 2007). It is an unpleasant sensation that has been described as tiredness, weakness, exhaustion, and lack of energy often caused by lasting stress (Lee et al., 2007). Even when patients have enough sleep, they may still suffer from exhaustion, physical weakness and little motivation for activity (Merkus et al., 1999). Fatigue is an ever-present reality for people with ESRD creating adjustment demands.

Mental health issues were stated by the pre-transplant group as a barrier to adjustment. Majority of the participants in the pre-transplant group had initiated counseling and medical treatment for mood disturbances upon initiation of dialysis. Estimates of prevalence of depression in the ESRD population are particularly high, suggesting that 12-40% of ESRD patients meet the diagnostic criteria for a mood disorder, with depression symptoms being highest among patients treated with hospital hemodialysis (Christensen et al., 2002). As patients with ESRD are at risk for experiencing depression, it is important to screen for adjustment demands and strategies. Early detection will lead to early intervention and treatment to ensure patients are able to live a healthy life.

Participants in the pre-transplant group described the lack of validation and support for their illness, specifically from co-workers, creating further grief and frustration. At a time when compassion, support and empathy are required, participants were met with criticism and disbelief. Adjustment to ESRD may be compromised by what Landsman (1975) refers to as the "marginal man syndrome." Most ESRD patients appear "healthy" despite being chronically ill. This results in people in their life having unrealistic expectations of their abilities, and expecting more of them than is appropriate. A research study by Hatchett et al., (1997) showed that adjustment to chronic illness was made more difficult when patients' family, friends, and medical staff failed to understand the magnitude of their illness, and its effects. Patients perceived they were not able to meet others expectations which resulted in poor adjustment.

The pre-transplant group voiced waiting for a suitable kidney transplant as part of an uncertain future. Waiting for a transplant virtually meant putting life on hold. Stress can be related to not knowing whether a suitable donor will ever become available, continually waiting for notification of a potential donor, and dealing with the general unpredictability of the situation (Juneau, 1995). A study by Pelletier-Hibbert and Sohi (2001) also found living with uncertainty about the future as a major source of stress for patients living with ESRD. Starzomski and Hilton (2000), state that managing uncertainty associated with a disease or illness may be an essential task in adjustment. When events become familiar, uncertainty can be prevented or decreased (Starzomski and Hilton, 2000). Thus the longer a person lives with a disease, the less uncertainty they experience. This may explain why uncertainty regarding the future was not mentioned by the post-transplant group as an adjustment demand. Providing patients with meaning and context through education and support helps decrease uncertainty (Starzomski and Hilton, 2000).

Both groups stressed the importance of social support to facilitate adjustment during dialysis treatment. The literature with ESRD contains much research that supports the claim of social support aiding with the adjustment to kidney disease and treatment. Research by Starzomski and Hilton (2000) showed that social support is crucial to assist with adjusting to life on dialysis, and transplantation. A supportive family and social environment has been identified as a particularly important source of social support for the chronically ill individual (Christensen et al., 2002; Whittaker, 1984). Chronic illness in a family invariably affects all members of the family.

It has been suggested that the way in which the family responds to or adjusts to an illness, impacts upon the patient's adjustment as well (Binik et al., 1990). Christensen et al. (2002) found that patients receiving a living related donor kidney, and who reported a more supportive family environment exhibited less depression, improved mobility and improved social functioning. However, living donor recipients reporting less family support exhibited increased depression, diminished mobility and impaired social functioning after transplantation. The treatment of chronically ill patients cannot be carried out without consideration of the patient's family and social environments (Vopel-Lewis et al., 1990).

Education and knowledge was also identified as key to assisting with adjustment. Report of education sessions focusing on increasing patients' knowledge about the basic pathophysiology of kidney disease, the role of dietary management in renal failure, and the options for renal replacement intervention was associated with a 4.6 month delay in the need to initiate dialysis, compared to the control group (Christensen et al., 2002). As mentioned previously, education can also provide patients with meaning and context regarding their disease, thereby reducing uncertainty (Starzomski and Hilton, 2000). According to a study by Talas and Bayraktar (2004), continuing education and counseling services are essential after transplantation, as patients' knowledge and living practices are inadequate to lead healthy lives. Study results showed that only 35.2% of the sample knew the signs and symptoms of rejection, 55.2% stated they avoided sunlight, 56% exercised regularly, and only 52.8% of the sample listed forbidden foods correctly (Talas and Bayraktar, 2004)

Financial concerns were voiced by only the post-transplant group as an adjustment demand while on dialysis. Patients with ESRD are more likely to suffer from short and long term losses in productivity (Zelmer, 2007). Zelmer (2007), estimates in 2000 productivity losses due to morbidity were $113 million for patients on hemodialysis, $33 million for patients on peritoneal dialysis and an additional $3.3 million for kidney transplant recipients.

The most significant adjustment demands recognized by participants during transplantation include side effects of medications, risk of rejection and expectations. Side effects of immunosuppressive medications were communicated by both groups as the major barrier to adjustment after transplant. Lindqvist et al. (2000) study on renal transplant recipients concluded the most frequent stressors as the cost of healthcare, weight gain, long-term side effects of anti-rejection medications, worried that changes in appearance would affect social life, limitations of physical activity, fear of repeated hospitalizations, risk of infections, fear of rejection, and uncertainty about the future. Common stressors reported post transplant were fear of rejection (Baines et al., 2002; White et al., 1990), uncertainty about the future, cost of medication and medication side effects (White et al., 1990; Talas and Bayraktar, 2004). Monroe and Raiz (2005) report additional concerns addressed by patients post transplant including issues related to donor death, being the recipient of another's organ, sexual dysfunction and depression. Zarifan (2006) found in regards to symptom occurrence and symptom distress changed body appearance, changed facial appearance, increased hair growth, and increased skin problems were the most frequently reported.

The length of time post transplant is also a variable in identifying stressors. Hayward et al. (1989) studied transplant recipients 6 months post transplant, and found the possibility of rejection as the most frequently reported stressor. Frey (1990) completed a similar study with patients from the same facility as Hayward et al. (1989). Patients however were 6 weeks post transplant, and identified the possibility of repeated hospitalization as most stressful.

Achille et al., (2004) summarized that previous research concludes that transplant related stressors fall into five broad categories: uncertainty about future health, finances, side effects of medications and physical constraints associated with their condition, interpersonal relations and medical follow-up and interactions with medical staff.

The literature is saturated with research on medication side effects. In a study by Talas and Bayraktar (2004), 67.2% of the patients developed anti-rejection drug side effects. These side effects include an increase in appetite, weight gain, hirsutism, an increase in perspiration, hand tremors, cushingoid face, and acne. These side effects have a drastic impact on the body image and self-esteem of patients. In a study completed by Zarifian (2006), renal transplant recipients reported sleep disturbances, fatigue, overeating, changed body appearance, and mood swings as the most distressing medication side effects.

A significant adjustment demand stated by the post-transplant group, but not readily found in the literature was that of expectations. Expectations encompassed assumptions about the actual transplant surgery, as well as expectations on life after transplant. Expectations regarding transplantation surgery included anticipating no complications, as well as presuming the length of time of convalescing in the hospital. Being provided with a “new lease on life,” the possibilities can be overwhelming as a person transitions from sickness to health. Savitch et al. (2003) describes a “crisis of good fortune” that may occur after transplant when the recipient becomes stronger, healthier and more independent. A person who has been ill for many years may have trouble reaching out for help as family and friends who regard the person as well now. This may result in interpersonal problems, and make the recipient feel that they are largely on their own after transplant. Landsman (1975) describes the challenge of adjusting when “suspended in a state of limbo between the world of the sick and the world of the well, belonging to neither, yet a part both…(questioning), am I sick or am I well?” (p. 268).

The pre-transplant participants were very focused on the prospects of transplantation having a positive impact on their life. An interesting study by Smith et al., (2008), showed that patients substantially overestimated the benefits of a successful renal transplant. Patients had specific predictions of life after transplant in areas of employment and travel that did not change at all after transplant (Smith et al., 2008). The tendency to overestimate the impact of a future event on one’s quality of life is referred to as an impact bias (Smith et al., 2008).

Limitations, Implications, and Recommendations:

Methodological problems that may have had an impact on study results include failing to control for socio-demographic factors, type of dialysis treatment modality, point of time in treatment, cause of renal failure, co-morbid conditions, and severity of illness. The participants were all English speaking individuals from one center. Kidney disease affects people of all ethnicities, so it would be ideal to study adjustment demands in a variety of ethno-cultural groups. Data was collected from one program, and thus may not reflect the experiences of all patients with ESRD. Also affecting results was including participants only with successful kidney transplants. Understanding the adjustment demands of patients with a failed kidney transplant, as they reinitiate dialysis, and the process to receive another transplant would be insightful. Since kidney disease and treatment impacts the entire family, inclusion of family members in future studies would be valuable. As adjustment is a process that takes place over time, it would be interesting to use a longitudinal design to study patient adjustment as they progress through the stages of kidney disease and treatment. Development of a holistic assessment of adjustment specifically for patients with ESRD would be effective to help with early detection and treatment of adjustment demands.

Conclusion:

ESRD is a significant and growing health issue in Canada and worldwide. Living with ESRD is a process of continual adjustment to an unpredictable illness. In order to achieve adjustment patients must make repeated efforts to change their lives to adjust to new circumstances imposed by their illness.

As health care professionals, our role is to encourage and enable patients to accept responsibility for their health and well-being. To provide effective patient care, it is imperative to develop an understanding of the phenomenological experiences of individuals with ESRD as they adjust to the magnitude of their illness. The research completed revealed the adjustment demands patients face as they progress through the stages of kidney disease and treatment. These findings will enable the healthcare team to anticipate challenges patients may face, and to provide the necessary support and education to foster positive adjustment. Study findings emphasize the need for interdisciplinary education, and support programs for patients during the pre, and continued throughout the post transplant stage. Adjustment demands are unique for each patient. To provide holistic care, the healthcare team needs to understand each patient's individual experiences, and assist with developing healthy strategies for adjustment to their illness. Patients can then find meaning and purpose in life that goes beyond the limitations imposed by ESRD to lead productive and satisfying lives.

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Chapter 3

Introduction:

During the researcher’s 10 years of clinical experience on the Northern Alberta Renal Program, huge variation was noted in patients’ ability to adjust to life after kidney transplantation. Some patients questioned whether they had made the right decision to receive a transplant. Complications post surgery such as leg weakness, diabetes, infections and hypertension resulted in longer hospitalization which took a huge toll on patients’ well-being. Upon discharge from the hospital, patients’ days were filled with multiple medical appointments. Patients were angry, because their expectations were transplantation was supposed to mean less time at the hospital compared to dialysis. Side effect of medications such as tremors, acne, erratic blood sugars, increased appetite and weight gain, had a tremendous negative impact on patients’ lives. Some patients faced challenges with the transition from being sick to being healthy. There was perpetual uncertainty as to activities they can and should be completing. Now that they were “healthy” the pressure of resuming roles and responsibilities was at times overwhelming. Observing this trend of patients’ challenges with adjusting to life after kidney transplant, with little to no evidence based research, was motivation to complete this research study.

The purpose of the study was to explore patients' adjustment demands as they progressed through diagnosis and treatment of End Stage Renal Disease (ESRD). Limited research was found in regards to adjustment specifically with kidney transplant recipients, and within the Canadian healthcare system. Much of the research was completed in Europe, Asia, and the USA. Additionally, no research studies were found involving Occupational Therapy intervention, and kidney transplantation. Adjustment as a construct is not clearly defined; hence each study utilized different indirect measures of adjustment. Furthermore, study results reported conflicting and inconsistent results. A large amount of the allied health research focused on comparing quality of life of patients on dialysis, versus recipients of kidney transplants. The vast majority of studies concluded quality of life improved upon receiving a kidney transplant.

A phenomenological qualitative study was completed to fully understand the lived experience of the participants. A sample of both pre and post kidney transplant participants were interviewed. An emphasis was placed on the adjustment demands post kidney transplant. Interviewing a mixed sample of pre and post kidney transplant participants allowed for interesting comparison between the real and perceived adjustment demands post kidney transplant.

Data Analysis:

Participants' responses were analyzed inductively using thematic analysis (Creswell, 2007). The method of analysis utilized to interpret the data followed a system based on a fourteen step method explained by Burnard (1991). The three phases included: 1) filtering and categorizing the data, 2) condensing, organizing and integrating the data, and 3) understanding and meaning.

Phase 1: Filtering and Categorizing Data

This phase consolidated stages 1-4 of Burnard's fourteen stage process. Transcripts were put into a table format, where field notes and memos depicting the researcher's impressions, and observations during the interview were written in the right hand column to assist with accuracy, and to serve as a reminder of the overall feel of the interview. The transcripts were then read with the intent of eliminating irrelevant information. Notes were made throughout on general themes that emerged within the transcripts (Burnard, 1991). The transcripts were re-read and headings or categories which captured all aspects of the content were written down. According to Burnard (1991), the process of headings or categorizing should account for all of the relevant interview data.

Phase 2: Condensing, Organizing and Integrating Data

This phase of analysis condensed stages 5-10 of Burnard's fourteen stage analysis process. The categories created in the first phase of analysis were narrowed down by removing similar or repetitive ones, resulting in a final list. Each transcript was again reviewed, and coded according to the categories listed. The categories were given a color code, and the information that was relevant to each category was coded with the same color. The color code sections of the transcripts were then placed together in the appropriate categories.

Phase 3: Understanding and Meaning

The third and final phase of the analysis considered stages 11-14 of Burnard's fourteen stage process, and included reconnecting with the study participants in order to share the categories. Subjects were contacted by telephone after the analysis in order to establish dependability of the researcher's interpretation. The comments from the subjects served as a continuous method for checking the trustworthiness of the data, and responses from the subjects were used to refine the categories and themes. These categories and themes formed the findings that were synthesized into a narrative summary report. The narrative under each category was linked and compared to what has been found in the literature regarding patient adjustment.

Credibility and Trustworthiness:

The primary focus in a study of this type is to gather a comprehensive and truthful representation of the phenomena (Depoy and Gitlin, 1998). To ensure the trustworthiness and credibility of the study, and to minimize the influence of researcher's interpretations or alterations of participants experience several strategies were utilized. These strategies included field notes, personal reflexivity, memos, member checks, and partial saturation.

A field journal was used to record thorough and detailed information of the participants' experience. The use of field notes ensured that important information was retained for the data analysis process. It also provided the researcher with useful examples and direct quotations that may be important to the results of the study (McReynolds et al., 2001).

Researcher bias was addressed using reflexivity during the data collection and analysis process through memos and reflection. Memos are a method used throughout the research process to address and record the researcher's personal biases, assumptions and feelings (McReynolds et al., 2001). The use of memos helped to protect against the loss of important perspectives during the research process.

Credibility was addressed by using member checks. Participants were contacted by telephone after analysis of the interview to verify accuracy of responses and researcher's interpretations. Member checks were also used to establish transferability of the data, and dependability of researcher's interpretations. Comments from the participants provided a continuous method for checking the trustworthiness of the data.

A constant comparison method was used to achieve partial saturation. This method involved comparing each new interview to the previous interviews. This process was used throughout the data collection phase until the point at which no new themes or categories emerged.

Clinical Implications for Occupational Therapy:

ESRD and treatment dramatically impacts patients' lives. Patients are faced with a multitude of stressors and must make significant adjustments to their way of life. Adjustment can be considered as an ongoing process which allows for harmonious functioning. Study results provided interesting and insightful knowledge regarding adjustment demands patients experience through diagnosis and treatment of ESRD.

The pre-transplant participants focused entirely on the advantages of kidney transplantation. Patients maintained a kidney transplant would mean getting back their health and independence. Only one participant mentioned the risk of rejection. The tendency to overestimate the impact of a future event on one's quality of life is known as impact bias (Smith et al., 2008). As one participant explained, she has gone through the kidney transplant teaching class, and is aware of the advantages and disadvantages of transplantation, but she chooses to look at it through rose colored glasses. Education and support is needed during the pre-transplant stage to maintain realistic expectations, while still maintaining hope.

Many similarities were noted with adjustment demands during dialysis found in the literature and the research study. Fatigue, mental health issues, uncertain future, dietary restrictions, inability to travel and financial strain appeared to be universal adjustment demands. Occupational Therapy can play a vital role with education on energy conservation techniques and goal setting to manage fatigue. Screening for mental health concerns and financial issues will allow for timely intervention. Goal setting and continual education and support will ensure compliance with dietary restrictions. Assisting with pursuing leisure activities will allow for fun and enjoyment. Additionally, education on travel options for individuals on dialysis is vital.

Education and support is vital to assist patients in managing side-effects of medications, and risk of rejection post-transplant. A common theme that emerged in the study was that of expectations after transplant.

Participants' expectation was that transplantation surgery and recovery would be uncomplicated. Additionally, there was a discrepancy with perceived and actual life after transplantation. Patients described the challenges of transitioning from being sick to being well. Not only did patients have their own expectations to contend with, but also the real and perceived expectations of friends, family, the healthcare team, and co-workers. Education and support is essential to assist with expectations. Additionally, setting realistic and achievable goals both pre and post transplant may assist with maintaining realistic expectations.

The research study exposed adjustment demands participants contend with as they progress through diagnosis and treatment of kidney disease. Although common themes arouse, adjustment demands are unique for each individual within their environment. In Occupational Therapy, patients are viewed holistically and every patient is treated as a unique individual. There are no preconceived biases about how the patient should feel or act. Rather, the patient's unique life context, experiences and life story is understood. This assists in recognizing the patient's response to the adjustment demands imposed by kidney disease and treatment. Occupational Therapy promotes participation, exchange of information, decision-making by the patient, and respect for the patient's choices as the patient is considered the expert on their life. Providing holistic care means understanding each patient's individual experiences, and assisting them with developing healthy strategies to adjust to their illness.

The rehabilitation of patients cannot be considered in isolation from their social environment, as this element is crucial to the adjustment to both kidney disease and treatment. As such, it is necessary to work not only with the patient, but also with the patient's family as they too may be experiencing detrimental effects from the disease and treatment.

Support is provided by listening, affirming and educating. Opportunities are created for peer education and camaraderie so that patients may learn from each other, and share their experiences. This facilitates hope, optimism, and feelings of belonging. Occupational Therapy empowers patients to find meaning and purpose in life that goes beyond the limitations imposed by ESRD, to lead productive and satisfying lives.

Limitations:

Methodological problems that may have had an impact on study results include failing to control for socio-demographic factors, type of dialysis treatment modality, point of time in treatment, cause of renal failure, co-morbid conditions, and severity of illness. A possible limitation could be in terms of who volunteered to participate in the study. It may be that patients who have only adjusted well chose to participate in the study. The primary investigator was the participants' Occupational Therapist. Participants may have altered their views or experiences to appease the Occupational Therapist. On the other hand, the purpose of the study was to understand participants' lived experience which may have been facilitated by having an established relationship and rapport with the participants.

Only English speaking participants from one center in Canada were included in the study. ESRD affects people of all ethnicities, so it would be ideal to study adjustment demands of patients from a variety of ethno-cultural groups. Data was collected from only one program, and thus may not reflect the experience of all patients with ESRD. Also affecting results was including patients only with successful kidney transplants.

Future Implications and Recommendations:

Limited research has been completed in regards to adjustment with kidney transplant recipients in Canada, and no research has been completed in Occupational Therapy with kidney transplant recipients. Not only will study results enhance evidence based practice in Occupational Therapy, but also within the Northern Alberta Renal Program. In order to provide effective patient care it is imperative to develop an understanding of the phenomenological experience of the individual with ESRD as they attempt to adjust with the magnitude of their illness and treatment demands. Since there is no cure for ESRD, the goal is to enable patients to achieve their highest level of functioning. Identifying patients' adjustment demands and strategies is essential to provide holistic care. The ability to adjust to ESRD will result in patients finding meaning and purpose in their life that goes beyond the limitations imposed by their illness (Christensen et al, 2002).

Completion of a quantitative longitudinal study on adjustment demands with a larger and diverse sample would be beneficial. It would be interesting to study the affects of socio-demographic factors, cause of renal failure, co-morbid conditions, and type of dialysis treatment on adjustment. It would also be beneficial to include spouse and family members in future research studies as ESRD impacts the entire family. As adjustment is a process that takes place over time, it would be interesting to use a longitudinal design to study patient adjustment over time as they progress through the stages of kidney disease and treatment. Development of a holistic quantitative measure of adjustment specifically for patients with ESRD would be beneficial to help with early detection of adjustment demands.

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