The psychological effects of dialysis on the patient and their partner

Yvonne White

University of Wollongong

UNIVERSITY OF WOLLONGONG

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THE PSYCHOLOGICAL EFFECTS OF DIALYSIS
ON THE
PATIENT AND THEIR PARTNER

A Thesis submitted in partial fulfillment of the requirements for the award
of the degree

MASTER OF NURSING (HONOURS)

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By
YVONNE WHITE  R.N. BNsg.

DEPARTMENT OF NURSING

1998
ABSTRACT

In the early 1960's technology promised to extend life when previously death was the only path for those with end-stage renal disease. In the 1990's dialysis as a form of renal replacement therapy is safe and efficient and provides a life-sustaining function for those in end stage renal failure.

There has been considerable research into the psychological effects of dialysis. Many studies have investigated quality of life issues, depression and compliance within those with end-stage renal disease. However, there has been little research conducted on the psychological effects of this life-sustaining high technology procedure and the patient/partner dyad. The majority of research into the psychological impact of dialysis has investigated the patient and partner groups as separate entities. Clinical experience suggests that the negative psychological impact of the dialysis procedures is pronounced for both patient and partner. Home dialysis requires the co-operation and assistance of a partner or support person in the procedure, and the impact on them has seldom been researched.

The first goal of this study was to investigate the dialysis patient and partner dyad in connection to the psychological impact dialysis has made on them. Depression and anxiety are well recognised reactions within the dialysis patient and to a lesser degree in the dialysis partner. The degree to which depression and anxiety has been influenced by factors such as neurological impairment, the patient/partner dyadic relationship, severity of renal disease, and the individual’s perception of their illness has not been investigated in one study before. The second goal of this study was to conceptualise the results within a comprehensive biopsychosocial model, and to present a uniquely Australian perspective. A cross-sectional descriptive comparative
study design was used.

Fifty-two people consented to participate in the study. There were 22 dyads (patient and partner), and a further 8 patients who either did not have a partner, or their partner was unwilling to participate in the research. There were 3 patients on in-centre haemodialysis, 1 on self-care haemodialysis, 6 on home haemodialysis, and 20 on home peritoneal dialysis. All were from the Illawarra Area Health Service of New South Wales. One patient, who consented to participate, was later excluded from the study due to significant cognitive impairment.

Patients were interviewed and asked to complete questionnaires relating to demographic information, cognitive function and behavioural changes (The Psychogeriatric Assessment Scales and the Color Form Sorting Test), depression (the Beck Depression Inventory and the Cognitive Depression Inventory subset), anxiety (the Beck Anxiety Index), dyadic relationship (the Dyadic Adjustment Scale as modified by Sharpley and Cross 1982), severity of renal disease (the End-Stage Renal Disease Severity Index), and perception of health (the Medical Outcomes Study Short Form 36). The partner group was not assessed for cognitive function, behavioural change, or severity of renal disease. Speech samples were also collected from each group, transcribed and thematic analysis was undertaken.

It was found that there is a significant level of depression and anxiety in the patient group. Levels of depression and anxiety were markedly lower in the partner group when compared to that of the patient group. There was no significant correlation between depression and anxiety and time on dialysis, but there was significantly more depression in the haemodialysis patient group when compared to the peritoneal dialysis group. There was also no significant relationship between depression and anxiety and the severity of renal disease, haemoglobin, or serum urea levels. However,
there was a significant relationship between depression and anxiety and serum creatinine levels. There was no significant relationship with dyadic adjustment and depression and anxiety. The patient group perceived their health as poor and was markedly below that of comparative age and medical disability groups. Partners perception of their health was comparable to that of their age group. There was no relationship between the levels of depression and anxiety across the two study groups.

Analysis of the verbal samples indicated that the physical decline associated with dialysis and the impact of dialysis itself were the major concerns to the patients. The partners indicated that the impact of dialysis, social isolation, and life-style changes were the major issues of concern to them.

This study suggests that there is a significant level of depression and anxiety in dialysis patients. But it is extremely difficult if not impossible to conclude if depression or anxiety are indicators of disease severity rather than true psychiatric disorders. This is supported by the very significant correlation between the BDI, the BAI, and the MOS SF-36, and the percentage of patients who indicated impairment on the somatic items of the BDI. The speech samples also indicated that the loss of physical abilities was the major issue of concern to patients. Results further suggest that the partners have been significantly effected by dialysis, especially those partners of haemodialysis patients.
ACKNOWLEDGMENTS

I wish to thank all those people who have helped to bring this thesis to completion.

Dr Brin Grenyer my supervisor whose invaluable advice, encouragement, and assistance has contributed greatly to the final result. Brin provided direction and set mutually acceptable goals which enabled me to complete the thesis. His sense of humour, and ability to explain concepts in simple language assisted in maintaining the motivation needed to complete this research study.

The dialysis patients and their partners who agreed to participate in my study. Each of these people gave freely of their time, and without whom this study would not have been possible.

The staff of the Department of Renal Medicine at the Wollongong Hospital for their support and assistance. Special thanks to Dr Maureen Lonergan, who agreed to be my co-supervisor at the hospital level. To Dr. Mackie and to the nursing staff of the in-centre haemodialysis unit, self care unit, and home training unit for their support and help in the selection of participants for the study; and to the clerical support staff (Mary and Karen) for arranging to have medical records at the renal clinics which enabled me to review specific records in comfort.

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To my fellow post-graduate students for their support, encouragement, and understanding during times of stress especially towards the end of my study and the writing of the thesis.

To Marion Martin and Dr John Sibbald for facilitating the post-graduate sessions over the two year period of my study. Without the supportive, encouraging, and informative environment provided by them this thesis would not have been possible.

A very special thank you must go to my family. In particular my mother who has had to put up with various pieces of paper and books strewn throughout the home for two years; my Grandmother (deceased) without whom I would not have pursued a career in nursing; and to my brother who cannot understand this thesis nor the reason for it, but who expresses pride in his sister in the oddest of ways.
# GLOSSARY OF TERMS

## DIALYSIS AND RENAL DISEASE

<table>
<thead>
<tr>
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<th>Description</th>
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<tbody>
<tr>
<td>ANZData</td>
<td>Australian and New Zealand Dialysis Data</td>
</tr>
<tr>
<td>APD</td>
<td>Automated Peritoneal Dialysis</td>
</tr>
<tr>
<td>CAPD</td>
<td>Continuous Ambulatory Peritoneal Dialysis. This mode of dialysis is generally performed by the patient within their own home.</td>
</tr>
<tr>
<td>ESRD</td>
<td>End Stage Renal Disease</td>
</tr>
<tr>
<td>GFR</td>
<td>Glomerular Filtration Rate</td>
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<tr>
<td>HD</td>
<td>Haemodialysis</td>
</tr>
<tr>
<td>SELF-CARE HAEMODIALYSIS</td>
<td>That mode of dialysis where the patient attends a 'minimal' care unit and performs their own dialysis with minimal assistance from the nursing staff. These patients are unable to dialyse within their own homes for various reasons.</td>
</tr>
<tr>
<td>IN-CENTRE HAEMODIALYSIS</td>
<td>That mode of dialysis where the patient attends a dialysis unit within a hospital and the dialysis is totally managed by the dialysis nursing staff.</td>
</tr>
<tr>
<td>HOME HAEMODIALYSIS</td>
<td>That mode of dialysis where the patient and their partner manage the patients haemodialysis within their own home</td>
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<td>Beck Depression Inventory</td>
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<td>CDI</td>
<td>Cognitive Depression Inventory</td>
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<td>CFST</td>
<td>Color Form Sorting Test</td>
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<td>DAS</td>
<td>Dyadic Adjustment Scale</td>
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<td>ESRD-SI</td>
<td>End Stage Renal Disease Severity Index</td>
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<td>Medical Outcomes Study Short Form 36</td>
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CHAPTER ONE

INTRODUCTION

"...Learn to balance the material wonders of technology with the spiritual demands of human nature...”

In the early 1960’s technology promised to extend life when previously death was the only path for those with end-stage renal disease. Scribner, a noted North American nephrologist, said that “...as long as the struggle for survival was the main issue, emotional problems were suppressed...” (Levy 1996,678). Although dialysis in the 1990’s is a safe and efficient support therapy for those with end-stage renal disease, it may be that emotional problems are still being suppressed in the day to day struggle with the restrictions and life-style changes, which are imposed by dialysis.

There has been considerable research into the psychological effects of dialysis. However, the majority of this research has investigated dialysis patients and their partners as separate entities. Many studies have investigated quality of life issues, depression, and compliance with within the end-stage renal disease population. There have been few research studies in which the psychological effects of long-term life-sustaining and high technology procedures (such as dialysis) have been reported. Clinical experience suggests that the negative psychological impact of the procedure is pronounced for a large number of people. The dialysis procedure may be performed second daily (in the case of haemodialysis), or multiple times on a daily basis (as with peritoneal dialysis). Home dialysis requires the co-operation and assistance of a partner or support person in the procedure, and the impact upon them has seldom been researched.

Literature shows that there is confusion about the rates of depression, especially in regard to the exclusion or inclusion of somatic items in assessment of medically ill
people. Dementia has been widely reported in the literature as a consequence of
dialysis and is often overlooked as an exclusion factor in studies of depression in the
person with end-stage renal disease. No study could be found which investigated the
patient/partner dyad, only the impact of dialysis on the patient and partner
separately. Studies have not systematically differentiated types of dialysis and their
effects. Furthermore, there has been few studies of anxiety or severity of renal disease
in end-stage renal disease included in reported psychological studies. Literature
further shows that there is a direct association with the way an individual perceives
their health and their psychological reactions to illness.

Therefore this study aims to improve our knowledge of this area by investigating the
incidence of depression and anxiety in dialysis patients and their partners and any
correlation between the dyadic relationship, the severity of renal disease, and the
perception of health.

The intention of this study was twofold. First, to investigate the patient and partner
diad in connection to the psychological impact dialysis has made on them. Depression
and anxiety are well recognised reactions within the dialysis patient and to a lesser
degree in the dialysis partner. The degree to which this depression and anxiety has
been influenced by factors such as the patients’ cognitive function, the patient/partner
dyadic relationship, the severity of the patient’s renal disease, and the individual’s
perception of their own health has not been investigated in one study before. Second,
to conceptualise the results of this study within a comprehensive biopsychosocial
model. The format of this thesis passes through the literature reviewed, methodology,
results, and conclusions reached.
BACKGROUND TO PRESENT STUDY

Current clinical practice in Renal Medicine in Australia advocates home dialysis as a better choice of dialysis for those patients who meet training criteria. The New South Wales Department of Health (1996) supports this view. Significantly, home haemodialysis patients have a better quality of life than other forms of dialysis (Disney 1996,43).

Forty-seven percent of all dialysis patients within Australia dialyse at home and 21% of all patients on dialysis within NSW dialyse at home. This accounts for 908 people (Disney 1996, Appendix 1, 26).

Clinical experience has shown that patients and their partners experience on-going stress in relation to dialysis, especially within their home environment. There is very little research conducted on the psychological effects of this life sustaining technology procedure on dialysis patients and their families. Clinical experience suggests that the negative psychological impact of the dialysis procedure is pronounced for a large number of people. Home dialysis requires the co-operation and assistance of a partner or a support person in the procedure, and the impact on them has seldom been researched. Therefore a study to investigate the psychological effects of dialysis on the patient and their partner was undertaken.

AIMS AND SIGNIFICANCE OF THE STUDY

The principle aim of the study was to investigate the incidence of depression and anxiety in dialysis patients and the patients' partners.
The relationship between the incidence of depression and anxiety, the severity of renal disease, the relationship between the patient and their partner, and the individual's perception of their own health was also a focus of study.

The results of this study will add to the information already available in relation to depression and anxiety in end-stage renal disease. In particular it will give an Australian perspective. There are few studies currently available which address the Australian situation.

This study investigated the relationship, of studied variables, between the patient and their partner. There are no studies, which have done this previously. Most research centred on the patient as an independent person and has not considered the dyad of the patient and their partner. The results of this study will provide an insight into the unique relationship between the dialysis patient and their partner and the effect this has on their adaptation to chronic end-stage renal disease.

STUDY NULL HYPOTHESES

1. There is no evidence of clinical depression and/or anxiety in the two sample groups.

2. There is no relationship between the incidence of depression and/or anxiety and the severity of renal disease, the relationship between the patient and their partner, and the individual's perception of their own health.
OBJECTIVES OF STUDY

1. To identify the incidence of depression and/or anxiety in the dialysis patient and their partner and to investigate if there is any relationships between study groups or across dialysis treatment modalities.

2. To identify any relationship between the incidence of depression and/or anxiety and the severity of renal disease in the two study groups.

3. To identify any relationship between the incidence of depression and/or anxiety and the dyadic association between the dialysis patient and their partner.

4. To identify any relationship between the incidence of depression and/or anxiety and the individual’s perception of their own health.
"In health there is freedom. Health is the first of all liberties."
(Henri Frederic Amiel, 1866)

PREVALENCE AND PROFILE OF RENAL DISEASE IN AUSTRALIA

In 1994 renal dialysis admissions to all Australian hospitals accounted for 230,000 admissions per year (The Australian Institute of Health and Welfare 1996,159). This was the leading cause of admission. If day only admissions were removed from this statistic, then renal dialysis was the second leading cause of admissions, second only to normal deliveries (The Australian Institute of Health and Welfare 1996,158). There is no reason to expect this rate to have declined, as the ANZData (1996, ) has demonstrated a trend that expects an annual 10% increase, in persons entering a dialysis program, per year.

In December 1995 there were 4,494 persons who were dialysis dependent in Australia and there were 1358 new patients admitted to dialysis programs. Of these new patients, 32% were 65 years of age or older (and there was a 50% increase in the age group 75-84). The most common cause of renal disease remains glomerulonephritis (35%), followed by diabetic nephropathy (20%), hypertension (8%), and analgesic nephropathy (7%). Fifty per cent of dialysis dependent patients aged less than 65 years are awaiting renal transplantation. The overall death rate of dialysis dependent patients was 11.6%, causes of death included: cardiac failure (45%); infection (15%); and withdrawal from treatment (17%). Of those who withdrew from treatment, 72% were in the greater than 65 years age group (Disney,1996:2-4).

Of the 4,494 people receiving dialysis therapy in 1995, 72% were dialysed out of hospital. Of these, 47% were home dialysis and 25% satellite dialysis. Of all dialysis dependent patients 31% were using continuous ambulatory peritoneal dialysis.
(CAPD), 28% used hospital based haemodialysis, 25% satellite dialysis, and 14% home haemodialysis (Disney 1996,73).

WHAT IS RENAL DISEASE?

The function of normal kidneys include nitrogenous waste product excretion, water balance, acid-base balance, and various hormonal regulatory functions which aids in blood pressure control, erythropoiesis, and calcium absorption. The aim of all these normal functions is to maintain homeostasis. If these regulatory mechanisms are impaired than homeostasis is not possible and death will ensue.

End-stage renal disease (ESRD) is that point at which the kidneys are no longer able to maintain homeostasis usually as a result of a chronic disease process of the renal tissue. ESRD is generally defined when there is a creatinine clearance of < 5mls./min. and no conservative measures such as diet and fluid control will prevent death. The loss of homeostasis in ESRD is primarily a result of a decrease in glomerular filtration rate (GFR). The physiological problems associated with ESRD include: i) retention of nitrogenous waste materials (urea and creatinine in particular); ii) water retention; iii) metabolic acidosis; iv) hormonal dysfunction which results in hypertension, anaemia and calcium/phosphate imbalances; and v) decreased life functioning as a result of the inability to maintain homeostasis.

The complex effects of a decreased GFR on physiological processes within the body can be demonstrated by the flow chart in Figure 1.1. (flowchart citation is unknown, but Daugirdas and Ing (1994) support information contained therein.)

At this point in time the patient will have the following symptomatology:

- nausea and vomiting;
- anorexia;
The Psychological Effects of Dialysis on the Patient and their Partner
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Figure 1.1
EFFECTS OF A DECREASED GLOMERULAR FILTRATION RATE (GFR)

DECREASED GFR

DECREASED URINE OUTPUT

INCREASED ANTI-DIURETIC

INCREASED BLOOD UREA and CREATININE

INCREASED FLUID RETENTION

Increased CO
Decreased Arterial pH and CO₂

Metabolic Acidosis

Anorexia
Nausea
Vomiting

Pruritis

Generalised Oedema

Increased susceptibility to infection

Increased urinary Acid and Ammonia
Decreased HCO₃⁻

Increased CO₂

Anorexia
Nausea
Vomiting

Increased susceptibility to infection

Muscle Weakness

Increased Serum K⁺

Cardiac Arrhythmias

Shock

Decreased Intravascular Volume

Respiratory Failure

Pulmonary Oedema

Cerebral Oedema

Increased PO₄ Retention

Neuromuscular Irritability

Increased Serum Calcium

Decreased Clotting Time

LETHARGY
COMA
DEATH

Source Unknown
nocturia;
poor nocturnal sleep pattern;
lethargy and fatigue;
poor neurological function (cognition, memory, concentration); and decreased sexual function.

In the past people died when they reached ESRD, but now due to the technological advances since the 1950's renal replacement therapy is available. Therefore it can be said that the disease entity ESRD has occurred as a result of technology being able to artificially sustain life functioning (Plough, 1980). There are two forms of renal replacement therapy available: renal dialysis and transplantation. Renal replacement therapies are only supportive therapies and should not be considered curative therapies.

DIALYSIS

Dialysis in general refers to the process of the removal of uraemic toxins from the blood via a semipermeable membrane. On one side of the membrane there is blood, and on the other a dialysing solution which consists mainly of physiological salts. Uraemic toxins and excess water pass through the semipermeable membrane down their concentration gradient. To enhance this water and solute removal pressure can be applied to the dialysate side of the semipermeable membrane; this process is called convection.

In peritoneal dialysis the semipermeable membrane is the peritoneum itself and is a biologically compatible dialysis membrane. In the case of haemodialysis an artificial membrane is used and held within a housing and is referred to as the haemofilter or artificial kidney. This artificial membrane has some biocompatibility which allows a problem free dialysis in most instances. Dialysis membranes are made of different
materials, some of which are more bio-compatible than others. There is a risk, of course with each haemodialysis therapy session that an individual's immune system may be stimulated by the artificial membrane, the potting compound used to stabilise the membrane, or the agent/s used in the sterilisation process of the artificial membrane which may result in a hypersensitivity reaction (Daugirdas and Ing 1994).

HAEMODIALYSIS

Haemodialysis became possible in 1913 (Gutch, Stoner, and Corea, 1993:36) when Abel, Rowntree and Turner devised the first artificial kidney which dialysed blood. But it was not until 1943 that haemodialysis was in clinical medicine use, following the development of the first clinically successful haemodialysis by Kolff and Berk (Gutch et al,1993, 37).

Haemodialysis requires the use of sophisticated expensive medical technology to maintain an extracorporeal blood circuit to allow the 'dialysis' to occur. Before haemodialysis can be commenced access to the bloodstream must be available, and this is obtained by the fashioning of an internal fistula in most cases. A fistula is an anastomosis of an artery and a vein which allows arterial blood to be shunted into the venous system. The most common vessels for this anastomosis are the radial artery and the cephalic vein. This shunting causes arterialisation of collateral veins and these are the vessels which are cannulated to allow haemodialysis to occur.

Persons who are on a haemodialysis program are committed to three dialysis sessions per week. Each session is between 4-6 hours in length, this is the same whether the person dialyses in hospital or in their own home. Each session is separated by one to two days; for example a person may dialyse on Monday, Wednesday, and Fridays. For each session of haemodialysis therapy, there is unseen time involved. That is, the setting up and taking down of the dialysis equipment and the maintenance which is
required to ensure a safe and effective dialysis session. This adds approximately one and half-hours to the dialysis time. If the dialysis occurs within the hospital setting, then the nursing staff performs these extra functions, but if the person is dialysing within their own home than they, or their partners are expected to perform these functions. This adds a significant amount of time to the dialysis commitment apart from the therapy session itself.

Therefore for haemodialysis to occur the requirements are complex medical technology; specialised personnel; and if the patient is to dialyse at home they must have the learning capabilities and a partner to assist them.

PERITONEAL DIALYSIS

Peritoneal dialysis became theoretically possible at the end of the nineteenth century when the peritoneum was discovered to be a dialytic membrane (Gutch et al, 1993:211). The development of clinical peritoneal dialysis proceeded by the development of peritoneal dialysis catheters in 1965 by Weston and Roberts, and Tenckhoff in 1968; the development of commercially available peritoneal dialysis fluid in 1959; and the development of automated peritoneal dialysis systems in 1962 (Gutch et al, 1993:212).

The process of peritoneal dialysis involves the insertion of a peritoneal catheter into the peritoneal cavity and the infusion of 2-3 litres of fluid (dialysing fluid) into that cavity. The fluid is left indwelling for a period of time, usually 1 to 4 hours, and is then drained out and the cavity is again filled with fresh dialysing fluid. The dialysis occurs during the time the peritoneal dialysis fluid lies dwelling within the peritoneal cavity (Khanna, Nolph, and Oreopoulos 1993).
Continuous Ambulatory Peritoneal Dialysis (CAPD) is by far the most common peritoneal dialysis regime in Australia (Disney 1996,73). CAPD involves the completion of four peritoneal dialysis exchanges per day, with the fluid left indwelling in the peritoneal cavity for four hours. This procedure is normally performed within the patient's own home, and involves a commitment of approximately five to six hours per day, seven days a week. CAPD is relatively easy to learn and the exchange procedure is simple, the main complication of peritoneal dialysis is infections - in particular peritonitis (Khanna et al 1993,76).

In either form of dialysis therapy the patient has to be committed to it. If a patient with ESRD chooses not to dialyse, then death will ensue.

Dialysis is a supportive therapy, which may last several years to a lifetime. If the patient is on a transplant program there is the possibility that they may receive a kidney transplant and will no longer require dialysis therapy. If the patient is not on a transplant program, than dialysis is for the rest of their life. This latter prospect is extremely daunting for both the patient and their families, due to the impact of chronic illness which is interspersed with episodic life-threatening events.

PHYSIOLOGICAL CONSEQUENCES OF DIALYSIS THERAPY

The physiological effects of ESRD and dialysis therapy are complex and involve all the body systems. The longer the period on dialysis the more debilitating the complications of dialysis become. The consequences of ESRD and dialysis arise from the reduction in glomerular filtration rate, the increased secretion of the Renin, and decreased levels of erythropoieten.
PSYCHOLOGICAL CONSEQUENCES OF DIALYSIS THERAPY

Clinical experience and wisdom suggests that persons who are on dialysis programs and the close members of their families exist in a world of stress, living and coping with a chronic illness which is interspersed with episodes of life threatening illnesses. It is thought that this long-term stress effects physical and emotional health of both the dialysis patient and their partner. The reliance upon a machine for life is in itself an unexpected event in most people’s lives. There has been a dearth of literature reporting studies on the psychological aspects of dialysis. In the main these have been concerned with patient’s point of view. Some studies have addressed the effects of dialysis on the dialysis patient’s spouse. Most studies have addressed either group on a mutually exclusive basis. That is, there were no studies found which investigated the dialysis patient and their partner in a comparative study. The following literature considers the results of studies investigating the psychological impact of dialysis.
CHAPTER TWO

RESEARCH OF THE PSYCHOLOGICAL EFFECTS OF DIALYSIS

In the early 1960’s technology promised to extend life when previously death was the only path for those with ESRD. In 1964 Belding Scribner (a noted American Nephrologist) addressed the American Society for Artificial Organs, where he said:

"...Because patients and physicians were allies in a continual fight for survival, there was not much time to worry about much else... As long as the struggle for survival was the main issue, emotional problems were suppressed..." (Levy 1996, 678).

At this same time Scribner predicted that as the threat of death became less, emotional problems would escalate and become dominant, and the suicide rate would increase (Levy 1996, 678). This prediction was supported in 1971 when Abrams et al (cited in Levy 1996, 678-679) conducted a multi-centre study and found that suicide among haemodialysis patients was perhaps as much as 50 times higher than the general population. It was also in 1971 that the issue of voluntary withdrawal from dialysis was first addressed (Levy 1996, 679). Disney (1996) reported that 17% of dialysis related deaths were due to social reasons, one of which was the patient’s voluntary withdrawal from dialysis treatment.

Present dialysis therapy is much changed from that in the 1960’s, and provides for safe and efficient treatment. Clinical experience has shown that many persons who are on dialysis programs have an acceptable survival rate relatively speaking, and can be on dialysis for many years (a decade or more). This has lead to the dialysis patient and their families undergoing day to day living with a progressively debilitating chronic illness for which there is no cure only support therapy, for prolonged periods of time. The possibility of a kidney transplant may be anticipated for those who meet the criteria to undergo such major surgery. Unfortunately there are many dialysis
patients who are unable to have a transplant due to a combination of factors such as advancing age and co-morbid conditions. For those who are waiting for a transplant, the waiting period is unknown.

Chronic Illness

Chronic illness is a major cost to the Australian Health system (The Australian Institute of Health and Welfare 1996,60) as it is reported to be in the United States of America (Newby 1996,786). "It creates increased family stress, [and] requires constant adaptation by the family" (Newby 1996,786). Newby argues that typically chronic illness has an onset, which may be acute or gradual, a course that is progressive and may have periods of acute exacerbation, and an expected outcome of death at some stage. Those families, which have the experience of living with ESRD progress through the onset stage which, can be either acute or gradual, and they have to deal with periods of acute exacerbations of life threatening illnesses during the course phase. These episodic acute periods require that families are very adaptable and can move back and forward from stable periods of a chronic condition to periods of high stress associated with periods of acute and possibly life-threatening illnesses.

Larkin (1987,542) also suggests that chronic illness require many changes throughout the course of the illness. To aid adaptation to chronic illness factors such as care, technology, family relationships, life development stage, cultural values and beliefs, communication and economics have to be considered (Larkin 1987,542).

Kristjanson and Ashcroft (1994) studying cancer's effect on the family identified developmental challenges during the course of the illness such as problems with finances,
role changes, decreased physical abilities, and isolation. Another factor identified was that the carer may have their own health problems, which may be exacerbated by the stress of caring for family members with cancer. It is suggested that a family’s experience of cancer may change over time from a need to gather information regarding the illness in the initial stages, to one of concern for the patients comfort and emotional responses as the disease progresses. This may also be similar for those families of dialysis dependent patients. Kristjanson and Ashcroft (1994,5) suggested that “the dying phase may be more emotionally intense for family members than for patients”. Similar phases could also be expected within families of people with ESRD. Kristjanson and Ashcroft (1994,5) identified family needs during a cancer illness as i) to learn skills to care for the patient, rather than by trial and error; ii) to get information about the disease process and the care required above psychological support; and iii) to ensure the patient is comfortable and communication is maintained. Demands on families included: i) physical care and treatment regime; ii) the demands of everyday household tasks; and iii) the strain of being continuously on duty or ‘stand by’ for the development of problems.

Westbrook and Viney (1982) investigated the psychological reactions to the onset of chronic illness. They performed a qualitative and comparative study of two sample groups. The main sample (n=126) consisted of patients who were interviewed within one week of being admitted to hospital (or within a week of being transferred to a ward from the intensive care unit) with the onset of a chronic illness. The second sample were younger (18-47 years) than the first sample (middle aged to elderly). These interviews were than transcribed and analysed to ‘provide indices of peoples’ experience of events” (Westbrook and Viney 1982,901). The content analysis of these interviews were based
on scales developed by Gottschalk and Glesser (1979,1969), and the cognitive anxiety and origin and pawn scales developed by Viney and Westbrook. It was found that the patient sample group had feelings of anxiety, helplessness, anger and depression much higher than the younger comparative sample.

Depression and Anxiety in End-Stage Renal Disease

The term depression is well recognised and is usually associated with some life event, such as the death of a loved one. There are several definitions which describe a clinical depression, one is:

"...In Psychiatry depression is classified as a morbid sadness or melancholy. Depression is closely associated with low self-esteem and confidence. Early signs of depression are pessimistic statements about their illness, refusal to eat, diminished concern about personal appearance and a reluctance to make decisions. When patients are depressed they are likely to isolate themselves and avoid social contact even with those who are trying to help them. Severely depressed patients usually express three basic feelings associated with their mental state. These are physical inactivity and a lack of desire to socialise, feelings of worthlessness and loss of self esteem..."(Miller and Keane 1987, 337)

Differentiating between clinical depression in dialysis patients and a sad mood (albeit chronic) as a response to a specific life event (loss of health and lifestyle as a result of dialysis) is extremely difficult.

"...A clinical depression or a mood disorder is a syndrome...that is not a normal reaction to life's difficulties. Depressive and other mood disorders include disturbances in emotional, cognitive, behavioural, and somatic regulation. Depressive disorders should not be confused with the depressed or sad mood that is a normal response to specific life experiences - particularly losses or disappointments. These responses are transient and are not associated with significant functional impairment..."(Billings 1995,48)

Billings (1995,48) goes on to argue that depression is underdiagnosed in the medically ill and can have an incidence of between 12-36% in this group. He goes on to discuss why it is important to diagnose depression, his reasons are that depression:
i) produces unnecessary suffering;

ii) increases physical distress;

iii) leads to a decrease in physical and psychological functioning;

iv) leads to poor judgement;

v) may cause a decreased ability to comply with medical treatment; and

vi) may result in suicide.

Anxiety is another well used term in today’s society, and again as with depression it is very difficult to differentiate between anxiety which is a normal response to a given stress and clinical anxiety. Many of the diagnostic criteria for anxiety states are based on somatic responses. Anxiety can be defined as:

"...a multidimensional concept manifested as a somatic, experiential and interpersonal phenomena; a feeling of uneasiness, apprehension, or dread. These feelings may be accompanied by physical symptoms such as breathlessness, palpitations, trembling etc. Anxiety may be rational or irrational. Anxiety disorders are a group of mental disorders in which anxiety is the most prominent disturbance..." (Miller and Keane 1987, 82-83).

Israel (1986) proposes several different models of depression in the ESRD patient. These models included the ‘giving up’ syndrome; the learned helplessness theory of depression; and biological models of depression.

Hinrichson, Lieberman, Pollack, and Steinberg (1989) investigated depression in 124 haemodialysis patients. Results showed that suicide ideation and depressed mood were the best items to discriminate between nil, minimal, and major depression (Hinrichson et al 1989, 287). Symptoms which were least discriminatory between the three categories of depression were insomnia, weight loss, fatigue, and appetite loss (Hinrichson et al 1989, 287). The conclusion of this study was that when using
standardised criteria in patients with ESRD, major depression is difficult to diagnose due to confounding effects of ESRD itself and possible co-morbid medical conditions (Hinrichson et al 1989, 288).

Burton, Kline, Lindsay, and Heidenheim (1986) obtained data from 167 home dialysis patients. Results from this study suggest two 'profiles' of depression. Type I depression included those patients who were on home dialysis for a minimum of two years. Type I profile illustrated profound anxiety, a high level of self-depreciation, social introversion, and hypochondriasis. Type II depression was associated with those 37 subjects who died during the study period. Type II profile illustrated self-depreciation, a slightly elevated level of anxiety, and hypochondriasis.

Sacks, Peterson, and Kimmel (1990) discuss that there has been association reported between depression and a higher mortality risk. They pose the question whether the depression assessment tools may be measuring severity of disease rather than depression (1990, 31) which may account for reports of a high incidence of depression in patients with ESRD. Sacks et al (1990) set out to assess the levels of depression, severity of illness, perception of illness and role disruption in patients in ESRD and chronic renal insufficiency, and to determine any relationship between these variables. The sample consisted of 73 persons, 57 with ESRD (43 on haemodialysis and 14 on CAPD), and 16 patients with chronic renal insufficiency. The measures used included the Beck Depression Inventory (BDI) and the associated Cognitive Depression Inventory (CDI) for depression, the End-Stage Renal Disease Severity Index (ESRD-SI) to assess disease severity, the Illness Effects Questionnaire (IEQ) to assess the perception of illness, and the SAS-SR to assess role disruption. The major finding from this study was that the perception of illness is a better predictor of depression than is the severity of illness. This finding is consistent with two other
studies (Rosenberg et al 1988, and Wise et al 1982). There was no significant
difference between the variables for those on haemodialysis or CAPD. Sacks et al
(1990, 38) concludes "...cognitive interpretations or appraisals of illness are a
critical factor in the emotional and behavioural response to illness... Greater
attempts...to modify perceptions in patients may be needed...".

Kutner, Fair, and Kutner (1985) conducted a study of 128 dialysis patients (10 in centre
haemodialysis, and 18 home haemodialysis) to assess depression and anxiety in chronic
dialysis patients. Results were that over half the patients had depressive symptoms and
48% of patients had symptomatic anxiety (Kutner et al 1985,26). There was a strong
correlation between depression and anxiety (r = 0.69, p < 0.001)(Kutner et al 1987,27).
Results also suggested that depression decreases as the time on dialysis increases. The
authors also suggest that depression and anxiety are closely linked to the patient’s
physiological state, and may ‘exaggerate’ depression and anxiety scores if the measuring
instruments have many somatic items included (Kutner et al 1985,29).

Craven, Rodin, Johnson, and Kennedy (1987) studied 99 subjects on haemodialysis,
intermittent peritoneal dialysis, and CAPD. Their overall findings suggest that the ESRD
population have a higher risk of depressive disorders. A previous episode of major
depression was found in those who had major depression in this study. Most of these
major depressive episodes were likely within two years of commencing dialysis.
Interestingly this study showed that loss of appetite and weight were significantly related
to the presence of major depression (X^2 = 12.50, alpha 0.001). Loss of appetite and
weight are associated with ESRD and inadequate dialysis. In the 1980’s measures of
dialysis adequacy were being introduced. Craven et al (1985) do not discuss whether
dialysis efficiency was assessed. Physical symptoms, which are associated with depression, were not excluded in this study. Therefore the inclusion of the somatic items may have resulted in an exaggerated level of depression in this study.

**Depression and Survival in End-Stage Renal Disease**

Shulman, Price, and Spinelli (1989) studied the association between psychosocial factors and survival in the ESRD patient. 64 patients (38 hospital HD patients and 26 home HD patients) on dialysis for a mean time of 3.7 years (hospital HD) and 2.0 years (home HD) were interviewed using several measures which assessed perception of illness, mental health, and renal disease. Depression was assessed using the BDI and CDI. At the ten year follow up results revealed that there was an increased death rate in those patients who perceived themselves as i) being sick; ii) having a major disability; and iii) who had an elevated BDI score (1989, 948). They also found that fatigue whilst being the most common complaint, a distinction between a physical or psychological basis could not be made (1989,949). The overall finding was that “...the single best predictor of survival was the BDI…” (1989,950). Depression:

“...correlated with the breakdown of social support systems, complications of end-stage renal failure, high urea and creatinine blood levels in hospital patients, and unexplained fatigue...”(Schulman et al 1987 cited in Schulman et al 1989,953).

Burton, Kline, Lindsay, and Heidenheim (1986) also found that depression was a major predictor of survival within the dialysis group. “The deterioration from ‘renal patient’ to ‘dialysis patient’ results in progressively more difficult restrictions, crisis, and threats of personal loss”(Burton et al 1986,261).
Kimmel, Peterson, Weihs, Simmens, Boyle, Verme, Umand, Veis, Alleyne, and Cruz (1995) investigated behavioural compliance with haemodialysis patients. A sample of 149 hospital in-centre patients across three dialysis units was chosen after meeting selection criteria. 93% of the sample were Afro-Americans. The mean BDI score for the total sample was 11.8 (SD 8.1) which is in the range of mild depression. The CDI mean score was 6.8 (SD6.0). BDI scores had a strong positive correlation with CDI scores ($r = 0.94$, $p < 0.0001$). The BDI was negatively correlated with DAS scores ($r = -0.25$, $p < 0.02$).

Most patients were found to be relatively compliant with dialysis treatment time. It was difficult to quantify compliance using standard measures such as serum potassium and phosphorous levels and interdialytic weight gain, as these could be confounded by many factors such as metabolic acidosis and hormonal balance and dialysis treatment conditions. (Kimmel et al 1995).

Kimmel (1992) investigated depression as a mortality risk factor in haemodialysis patients. He prospectively looked at survival rates in 57 patients with ESRD. Forty-seven on haemodialysis and fourteen on CAPD. The assessment tools included the Beck Depression Inventory (BDI) and its subgroup the cognitive depression inventory (CDI). One year following the initial assessment, ten subjects had died. The CDI scores of those who had died were significantly higher than those who survived. At two years follow up, twenty one subjects had died and the mean age, BDI score and disease severity scores were significantly higher in those who had died. A hazards analysis showed that the CDI scores were independently associated with a higher risk of death (Kimmel 1992,698).

Kimmel concludes that,

"...Depression may simply be a marker of severity of underlying medical illness. Alternatively, the patient’s level of depression may modify physiological factors such as immunologic function, nutritional factors, compliance with treatment or
family dynamics which may conceivably affect the course of medical illness and the patient’s ultimate survival...” (1992, 699).

Psychosocial factors which may contribute to survival outcome include impaired psychoneuroimmunological functioning due to depression and emotional distress, group dynamics, family processes, suicide, voluntary withdrawal from treatment, and indirect self-destructive behaviour (Devins, Mann, Mandin, Paul, Hons, Burgess, Taub, Schorr, Letourneau, and Buckle 1990, 127-128). Devins et al (1990) conducted a study aimed at investigating quality of life and the psychological impact of ESRD. The study group final sample was 97 patients (37 in-centre, 16 home haemodialysis, 10 CAPD, 34 renal transplant), with a mean age of 40.3 years (SD 14.07). Information was collected from haemodialysis patients during their dialytic therapy session. Reported results failed to confirm other findings that depression is a significant predictor of survival in ESRD. The results identified four predictors of better survival in ESRD patients, these were: i) less serious non-renal co-morbid conditions; ii) younger age; iii) increased involvement in leisure activities; and iv) life happiness (Devins et al 1990, 132).

Possible Biological Bases of Depression in End-Stage Renal Disease
Depression can be a result of many factors from end-stage renal disease. Endocrine function is disturbed by the build up of uraemic toxins, which leads to a uraemic state. This loss of homeostasis, which occurs in ESRD leads to many neuroendocrine disturbances such as insulin resistance, hormonal dysfunction, neurotransmitter dysfunction, increased parathyroid hormone levels etc. It is not clear if these dysfunctions are related to abnormal production/release of these substances, or whether there is end organ resistance (Daugirdas and Ing 1994). These dysfunctions may have an effect on cognitive function and so foster depression. Cognitive function impairment has also been recognised for many years in dialysis patients.
An early paper by Stewart and Stewart (1979) discussed the uraemic effect on higher cortical functions in ESRD. They state that short term memory loss, decreased attention span, and decreased alertness are positively correlated with creatinine levels. These neurological effects of uraemia can be reversed by dialysis (Stewart and Stewart 1979, 525). Conditions, which may exacerbate this neurological dysfunction, are hypertensive encephalopathy, uraemic neuropathy, dysequilibrium syndrome on initiation of dialysis, and potential subdural haematomas as a result of anticoagulation in haemodialysis patients (Stewart and Stewart 1979).

Souheaver, Ryan, and DeWolf (1982) investigated the effects of uraemia on the neuropsychological functioning. They used the Halstead-Reitan Test Battery (HRB). The HRB assesses cognitive, perceptual and motor activities (1982, 490). The sample comprised three groups each with 24 subjects. The three groups were: i) a group of ESRD patients; ii) a group of patients with general medical conditions and/or non-psychotic conditions; and iii) a group of patients with chronic neurological disorders (1982, 491). Results suggest that the uraemic group and the neurological disorders group were similar in regard to adaptive abilities, which were dependent upon brain functions (1982, 494). The uraemic group scored better than the neurological group on auditory alertness and finger oscillation speed. The uraemic group and the neurological group were equally impaired on visual alertness, flexible thinking and speed of mental manipulations (1982, 494). The authors suggest:

"...that the uremic patients do not show an attention deficit per se - as long as the task that confronts them requires only passive and automatic reception of auditory stimuli and without effort to organise the material or to establish mnemonic devices...uremic patients experience great difficulty with novel problem solving tasks and are unable to deal rapidly and effectively with situations that require assimilation of two or more pieces of information simultaneously..." (1982, 495).

In a study by Gilli and Bastiani (1983) information was collected from a sample of 54
subjects who had been on haemodialysis for a mean of 31.29 (SD24.07) months, and had a mean age of 50.94 (SD7.86). The aim of this study was to assess the intellectual function of patients. Assessment was by using the Wechsler Memory Scale (WMS) and the Wechsler Adult Intelligence Scale (WAIS). The WAIS assesses general intelligence and reasoning (IQ), and the WMS evaluates memory function (MQ) (1983,189). All tests were done 24-36 hours after dialysis, and 21 subjects were tested twice with the second test being 12 months following the initial test. Reported results showed no correlation between neuropsychological tests, haemoglobin, urea, creatinine, Aluminium levels, or formal education (1982,189). Significant inverse relationships were found between: i) MQ and months on dialysis ($r = 0.43, p<0.01$); ii) MQ and parathyroid hormone (PTH) level ($r = 0.321, p < 0.05$); iii) performance IQ and PTH level ($r = 0.372, p < 0.01$); iv) an inverse correlation between MQ and months on dialysis at $t_1$ and $t_2$ ($t_1: r = 0.65, p <0.01$; $t_2: r = 0.6187, p < 0.01$) (1982,189-190).

Other possible causes of cognitive dysfunction in the ESRD patient are: anaemia, and sleep disturbances (Nicholls 1994,676-677). ESRD leads to a disturbance of the body’s diurnal rhythm and as a consequence day and night reversal (Kaupke and Vaziri 1994,602). This leads to insomnia, daytime somnolence, and other associated problems such as depression and decreased mental acuity (Kaupke and Vaziri 1994,602).

Sleeping pattern disturbances are common in patients with ESRD. Loss of sleep may lead to depression and increased day somnolence. Kimmel (1991,54) reports that the incidence of sleep apnoea in ESRD is as high as 75%. Kimmel further states that “satisfaction with sleep is an important determinant of one’s assessment of quality of life” (1991,52). He goes on to suggest that sleep disturbance may contribute to the
high incidence of depression found in ESRD.

Fishbein (1994,181) hypothesises depression may be due to an alteration in catecholamine regulation of the hypothalamic-pituitary-adrenal axis. This alteration then manifests as neurobiological and psychological problems (Fishbein 1994,182).

Other effects of dialysis may result in dementia. Aluminium poisoning in dialysis patients can lead to a progressive myoclonic dementia (Nicholls 1994,675). There are many strategies in place in current clinical renal medicine to reduce this effect. These strategies include better water treatment prior to its delivery to the dialysis machines and the minimal use of Aluminium based medications. However, if Aluminium poisoning is excluded progressive dementia is most likely to be due to multi-infarct dementia. This type of dementia results from the accelerated atherosclerosis, which is associated with ESRD. (Nicholls 1994,675).

Many studies which have examined the psychological consequences of dialysis, have ignored these possible cognitive deficits as a confounding variable in studies.

The Marital Dyad and its Effects on Dialysis Therapy

ESRD impacts enormously on the family. Family and marital relationships that have evolved prior to the patient becoming ill are altered by the presence and responsibility attached to caring for a person on dialysis. These alterations revolve around such factors as the dialysis therapy itself, both the patient and spouses perception of their own and each other health, social isolation, role disruption in the family, reliance upon complex medical technology, and the fear of death of a family member.

Chowanec and Binik's (1982) review of the marital dyad and ESRD found several
consistent themes: i) that the marital dyad is a key element in individual adjustment; and ii) that the individual adjustment of each spouse is inter-related (1982,1556).

Perception of Illness

"...Every individual is healthy in his or her own distinctive way and by the same token the most competent expert in his or her own health..."

(Haggman-Laitila 1997,46).

Increasingly patients are expected to perform complex medical procedures at home. This leads to less cost to the public healthcare system and allows the patient and their family to manage their illness. In the case of ESRD, being able to dialyse within the patient’s own home encourages a better quality of life (Disney 1996). This improved quality is related to the fact that the patient is able to be in their own environment, and are not tied to a set time regime for dialysis as they would be in the hospital setting. These factors should allow a patient and their family to maintain their usual psychosocial support systems within their local community.

Eitel, Hatchet, Friend, Griffin, and Wadhwa (1995) conducted a study aimed at evaluating the relationship between behavioural control over treatment and adjustment to chronic illness. A final sample of 98 dialysis patients was obtained (35 in-centre haemodialysis and 63 CAPD). Several measures were used including the ESRD-SI and the BDI and associated sub-set the CDI. The mean age was 54.91 for the haemodialysis group, and 54.52 for the CAPD group (1995,459). Overall findings of this study were that as disease severity increases for those in high control groups (such as home CAPD), depression also increases. With the low control group (in-centre haemodialysis), as the severity of disease increases depression decreases. The authors suggest that the low control group may receive more care and attention from medical and nursing staff when they are seriously ill which results in less stress (1995,461).
Illness Intrusiveness and Quality of Life

Devins, Mann, Mandin, Hons, Burgess, Klassen, Taub, Schorr, Letourneau, and Buckle (1990) studied 99 ESRD patients (n=39 on hospital HD, n=15 on home HD, n=11 on CAPD, and n=34 post transplant) to investigate illness intrusiveness and its impact on the quality of life. The three dialysis groups reported a greater level of illness intrusiveness than the post transplant group. This intrusiveness was related to physical well being and diet, work and finances, and marital and family relations (Devins et al 1990,127). The authors also report that “total perceived intrusiveness was significantly correlated with time requirements [for dialysis therapy],...uraemic symptoms..., non renal health problems,...fatigue..., and difficulties in daily activities...”(Devins et al 1990,131). These factors were more affected than either marital relationships or recreation and social relationships outside the family. Devins et al (1990,139) conclude “that the construct of illness intrusiveness may be an important mediator of quality of life effects in chronic, life-threatening illnesses such as ESRD”.

Christensen, Weibe, Smith, and Turner (1994) investigated the role of ESRD patient’s degree of perceived family support and reported depression as predictors of patient survival (1994,522). The final sample was 78 in-centre haemodialysis patients with a mean age of 53.98 years. Various measures were used including the BDI and CDI. Neither the CDI or BDI were significant predictors of survival, however a perceived high level of family support was significantly associated with better survival(p < 0.005) (1994,523). This finding is supported by a study conducted by Molassiotis, Van Den Akker, and Boughton (1997). Molassiotis et al found that persons who had a bone marrow transplant and had a high level of perceived support in social, family and psychosocial categories had a better survival rate (1997,317,323).

Wichowski and Kubsch (1997) investigated the relationship of perception of illness
and compliance was investigated. They sampled 106 subjects with an age range from 3-87 years. Each subject had a chronic illness (Diabetes Mellitus) for at least two years. Their results supported the premise that self-esteem was positively correlated with compliance by demonstrating a significant ($r = -0.33, P = 0.04$), but negative relationship between self-perception of illness and compliance for the total sample. The significance was even greater for adults ($r = 0.64, P = 0.001$), than for the children group (age < 18 years) ($r = 0.18, P = 0.25$).

Psychosocial factors which may contribute to survival outcome include impaired pschoneuroimmunological functioning due to depression and emotional distress, group dynamics, family processes, suicide, voluntary withdrawal from treatment, and indirect self-destructive behaviour (Devins, Mann, Mandin, Paul, Hons, Burgess, Taub, Schorr, Letorneau, and Buckle 1990,127-128). Devins et al (1990) conducted a study aimed at investigating the quality of life and the psychological impact of ESRD. The study group final sample was 97 patients (37 in-centre, 16 home HD, 10 CAPD, and 34 renal transplant), with a mean age of 40.3 years (SD 14.07). Information was collected from HD patients during their dialytic therapy session. Reported results failed to confirm other findings that depression is a significant predictor of survival in ESRD. The results identified four predictors of better survival in ESRD patients, these were i) less serious non-renal co-morbid conditions; ii) younger age; iii) increased involvement in leisure activities; and v) life happiness (Devins et al 1990,132).

A study to investigate quality of life and its specific dimensions was reported by Killingworth and Van Den Akker (1996) for dialysis patients. Their sample consisted of 170 subjects from one dialysis unit (100 CAPD, 70 haemodialysis). Multiple assessment instruments were used to assess physical and psychological dimensions.
Results suggest that there is a relationship between severity of ESRD and psychosocial states of anxiety, depression and quality of life. 40% of CAPD and 45% of haemodialysis patients had difficulty in adjusting to their illness.

In 1982 Kaplan De-Nour reported the results of a study of 102 dialysis patients. The aim of the study was to investigate psychosocial adjustment to illness. Results indicated that although subjects reported a higher incidence and severity of problems, they do use denial. This denial is not in relation to the severity of the problems, but in regard to the impact of those problems (1982,21). This denial was evidenced by patient’s reports regarding their relationships with other people (work colleagues, partner, and other family members). These reports indicated that the patients perceived good relationships. This finding was in conflict with “their severe decrease in vocational, domestic, sexual, and social functioning” (1982,21). This denial may also impact greatly on people around the patient (1982,21). Kaplan De-Nour provides a cautionary statement that the questionnaire which was used in his study “was useful in gathering information about...the functioning level, but much less so for...psychological distress and relationships” (1982,21).

In an Australian study of 111 dialysis patients, Lok (1996) distributed a questionnaire, which was aimed at assessing stressors, coping mechanisms and quality of life of the sample group. Results were reported from 64 patients (56 haemodialysis, 8 CAPD), accounting for a 58% questionnaire return rate. The mean age of the sample was 42.5 years. Results showed the most frequent stressor in both HD and CAPD patients was limitation in physical activities (1996,875), followed by a decrease in social life for HD patients, and sleep disturbance for CAPD patients (1996,875). Subjects quality of life was perceived to be much better in the CAPD patients than the HD. Overall results suggest that: i) that there was a negative
correlation of quality of life to total stressors (HD $r = -0.38$, $p<0.05$; CAPD $r = -0.54$, $p<0.01$), ii) HD patients had a negative correlation on both physiological and psychological stressors ($r = -0.56$, $p<0.01$ and $-0.28$, $p<0.05$ respectively) with quality of life; and iii) total stressors and psychological stressors increase as time on dialysis increases in haemodialysis, and only physiological stressors in CAPD (1996,880). The reported results from this study should be tempered especially in regard to the small sample of CAPD patients. A larger sample may have increased or decreased the significance of the findings.

Estwing-Ferrans and Powers (1993) conducted a study, which investigated the quality of life for haemodialysis patients. This was a large study, with a final sample of 349 from a potential random sample of 800. The sample was from 95/105 counties in the state of Illinois in the United States of America. The assessment instrument was the Quality of Life Index (QLI) which was designed by Estwing-Ferrans and Powers in the 1980’s. The survey was conducted via a mail out of questionnaires. Reported results showed relatively high scores (mean 20.70, SD 4.77) for the total QLI. This indicated that the patients surveyed were well satisfied with their quality of life. The mean score found in this study are reported to be just below scores gained from 88 healthy persons (mean 21.9) (1993,579). Ferrans and Powers suggest that the higher QLI score may be as a result of adaptation. The mean number of years on dialysis for the patients was 4.02 (SD 3.49). The authors further suggest that adaptation increases with the years on dialysis. Reported results also indicated that patients were least satisfied with the limitations (physical, dietary, freedom) imposed by dialysis (1993,578). They also found that poor financial status led to a negative effect on the individual’s quality of life (1993,580).

Klang, Bjorvell, and Clyne (1996) investigated 38 Swedish pre-dialysis patients from one specialist Nephrology unit. The aim of their study was to describe uraemic
patients' well being during the pre-dialysis stage of ESRD. Their findings include the most negative factor in the individual's perception of health was the feeling of decreased energy and general fatigue, and that a strong sense of coherence enabled individuals to perceive their health as better than those with a weak sense of coherence.

In the 1996 ANZData Report, Disney (1996,43) reported that those patients self-dialysing at home on haemodialysis had better activity ratings than all other forms of dialysis including those on home CAPD. Disney used the Karnovsky Quality of life assessment. The nephrologists and dialysis nurses who care for the dialysis patient, not the patient themselves make this quality of life assessment. He goes on to say that 17% of deaths were due to social reasons (eg. withdrawal from treatment) (Disney 1996,50).

In summary, results from a large number of international studies suggest that the cost of chronic illness to the health care system is high and that significant levels of stress (inherent in managing dialysis therapy) and adaptation occur within the dialysis who family. These adaptations are required for dialysis families contend with a chronic illness such as ESRD (Newby 1996; Kristjanson and Ashcroft 1994; Larkin 1987; and Westbrook and Viney 1982).

The literature also recognises that psychological factors are very important in the survival of ESRD patients. This survival is dependent on other co-morbid conditions, severity of renal disease, compliance with dialysis regimen (dialysis time, dietary and fluid restrictions, and medications), and a good psychological state. Depression is a major problem for the medically ill (Billings 1995). Studies report very conflicting incidences of depression in the dialysis patients (Hinrickson et al 1985; Burton et al
1986; Kutner et al 1985; and Craven et al 1987), which suggests that there is a wide spectrum of psychological responses to ESRD. Assessment of depression has been criticised because of the variation in assessment measures. The BDI and CDI were used in several studies with good reliability and validity (Sacks et al 1990; Craven et al 1987; Shulman et al 1989; Kimmel et al 1995; and Kimmel 1992). Assessment criteria for the diagnosis of depression rely upon many physiological responses. Not all studies investigated the impact of these somatic responses on the levels of depression found in the ESRD patients. Consequently reported results may have been exaggerated because of the confounding effect of somatic items. As many somatic depressive symptoms may also be associated with ESRD itself. Literature also supported the association of depression with a poorer survival outcome in those with ESRD (Burton et al 1986; Shulman et al 1989; Kimmel 1992; Devins et al 1990).

Many studies mentioned the impact of anxiety on dialysis patients but few actually reported any assessment of anxiety. Again a reliable assessment of anxiety in ESRD is difficult because of the confounding effects of the somatic items used in assessments.

The perception of health by the individuals was found to correlate with depression (Killingworth et al 1996, Kimmel 1992, Sacks et al 1990), and also with the severity of renal disease (Devins et al 1990, Killingworth et al 1996). However, it is very difficult to prove definitively if the levels of depression found in the dialysis patient is of cognitive or physiological origin. This situation can be compared with the 'chicken and egg' situation. Does the patient's physical decline increase the risk of a cognitive depression, or does cognitive depression impact on the physical abilities of the patient? The reviewed studies certainly indicate that there is a significant relationship between the patient's physical state and depression. However, is depression a marker of the severity of renal disease (Kimmel 1992)?
Effects of Dialysis on Spouses

As this review has demonstrated, dialysis has a number of negative psychological impacts on the patient. Yet we can expect that the partner will also likewise suffer a negative impact.

Burton, Kline, Lindsay, and Heidenheim (1988) also investigated perceived support. This study measured support as described by Cobb (1976) in that social support is 'information' that a person is loved and cared for, esteemed and valued, and part of a network of communication and mutual obligation. Burton et al (1988) reported results from a final sample of 232 ESRD spouses. The overall finding was that “social support has a direct and positive impact on minimising psychological dysfunctioning” (1988,262). Burton et al further selected a sample of 90 home dialysis patients > 65 years from the original sample for comparison with the total sample (n=232). Overall findings from this comparative function was that on social network, social support, and social integration the elderly group were similar to the younger aged (1988,264). Across the total sample there was a direct relationship between the spouses perception of social support and their own improved psychological functioning (1988,265).

Wagner (1996) conducted a comparison of families and registered nurses views of family needs of chronic haemodialysis in-centre patients. The sample consisted of two groups. One group consisted of 10 family members of ESRD patients; and the second group consisted of 9 Registered Nurses from one dialysis centre. The aim of this study was to investigate if there were differences in the two-sample group’s perception of psychosocial needs, and how identified psychosocial needs were ranked by the two sample groups. The results of this study identified two major psychosocial needs of families. These major needs were the need for information, and the need for comfort.
Nurses however did not think these were important. The author does discuss however, that nurses within the in-centre style dialysis unit may have very little contact with the patients families and therefore may be unaware of the identified needs.

Friesen conducted a descriptive study of home haemodialysis spouses. This study had a small sample of 8 spouses, seven of whom were female. Friesen was investigating four questions (1997,313), which included i) the experience of being a spouse of a home haemodialysis patient; ii) how does the spouse describe this experience; iii) how does the spouse describe the day to day living with home haemodialysis; and iv) what factors influence the spouses response to home haemodialysis. The data was collected from tape recordings of unstructured interviews, which were supplemented by field notes. Results acknowledged two themes throughout the interviews. These were the level of involvement and resentment. The level of involvement related to the spouses activities with the assisting with the dialysis procedure, and ...“was also reflective of the marital relationship”...(Friesen 1997,313-314). Resentment was also related to the level of spousal involvement with dialysis. In her discussion Friesen says: i) that the experience of being a home haemodialysis spouse affects all aspects of life; ii) that the marital relationship is affected and in turn impacts on home haemodialysis; and iii) home haemodialysis is more successful when spouse and patient share the responsibility for dialysis.

In their introduction Lowry and Atcherson (1984,293) state that spouses of dialysis patients have received less attention as study groups. They further state that spouses also experience loss, role changes, and financial problems as well as the patient. Along side these difficulties changes in the dyadic relationship also occurs. “Patients may not only decline in their interest and capacity for sexual involvement...but may
also become regressed, childlike, demanding and dependent" (Lowry and Atcherson 1994, 293). The literature review conducted by Lowry and Atcherson revealed several consistent findings: i) that spouse assistants felt deprived and hostile; ii) that these problems decreased as the spouse was trained for home dialysis with the patient; iii) many patients gave the major responsibility for their dialysis to their partners once they were home (1994, 294). The Lowry and Atcherson study of home dialysis patients and spouses involved 29 spouses and 32 patients. Each subject was assessed at three months and six months after the commencement of home dialysis. The major findings from this study were: i) depressive symptoms were uncommon in spouses after six months with home dialysis; ii) fatigue occurred less frequently than had been reported earlier; iii) some spouses reported that they were still nervous after the six months; iv) spouses said they were easy to anger; and v) marriage assessment revealed few or no problems (1994, 299). Lowry and Atcherson conclude that "it is conceivable that spouses assisting home dialysis patients for longer periods of time...may develop more frequent and/or serious psychological symptoms later in the course of maintenance treatment" (1994, 300).

Dunn, Lewis, Bonner, and Meize-Grochowski (1994) reported results of a study, which investigated the quality of life of spouses of CAPD patients. The sample consisted of 38 spouses. Instruments were chosen to measure quality of life (Quality of Life Index); ESRD severity (The End Stage Renal Disease Severity Index [ESRD-SI]); Marital adjustment (The Dyadic Adjustment Scale); and Coping strategies (Jalowiec Coping Scale). Results showed that 38% of the sample scored below average on marital adjustment; the mean score on the ESRD-SI was 22.3 (SD 14.6), much higher than that reported by Craven (1991) and his colleagues of 8.1-15.5. The overall findings of the Dunn et al study were: i) 79% of subjects perceived their quality of life in the moderate to poor range; ii) quality of life scores correlated with marital
adjustment (a positive correlation); iii) spouses perceived quality of life was affected by income; and iv) severity of illness was not correlated with quality of life (1994,244-245).

A study by Rideout, Rodin and Littlefield (1990) investigated depression in spouses of dialysis patients, severity of patient disease, level of stress experienced by spouses, and the perception of support from the ill partner. Fifty-six married couples were selected where the dialysis patient had been on dialysis for a mean time of 10.2 weeks (SD9.7). The majority of spouses were female with a mean age of 51 years (for both spouses and patients)(1990,41). Significant findings from this study suggest that patient illness severity was correlated with financial and social stressors for the spouse (r = 0.38, p < 0.01). Also spouse depression was negatively correlated with perception of support from the ill partner (r = -.57, p < 0.001), and correlated positively with the financial and social burden of the illness (r = .36, p < 0.01) (1990,42).

In summary, reviewed studies support the idea that spouse's quality of life can suffer due to their partner's dialysis. In particular the direct relationship between the partner's perception of social support and their psychological functioning (Burton et al 1988). The partner's level of involvement in the dialysis procedure leads to resentment of the patient and a decreased quality of life. As Lowry and Atcherson (1994) found many patients give the partner's responsibility for their dialysis, clinical experience supports this finding. The partner will also experience losses similar to those of the patient's (financial, social, role definition). Therefore the level of negative psychological impact of dialysis may approach that of the patient.
PRESENT STUDY

The literature review shows that:

1. there is confusion about the rates of depression, especially in regard to the exclusion of the somatic items. Thus there is a need for a study to carefully assess this;

2. dementia has been reported in the literature as a result of dialysis and is often overlooked as an exclusion factor in studies of depression in the ESRD patient;

3. no study has looked at the patient/partner dyad, only the impact of dialysis on the patient and partner separately

4. studies have not systematically differentiated different types of dialysis and their effects;

5. there has been few studies of anxiety or severity of disease associated with ESRD; and

6. the individual’s perception of their health is associated with their psychological status.

Therefore this present study aims to improve our knowledge of this area by:

i) investigating the incidence of depression and anxiety in dialysis patients and their partners, and any relationship between the severity of renal disease, the patient/partner dyad, and the individuals perception of their health; and ii) to conceptualise the results within a comprehensive biopsychosocial model.
CHAPTER THREE

THEORETICAL FRAMEWORK

The theoretical framework for this study involves two major concepts. The first being the development of a conceptual model from the literature review. The second concept is taken from the perspective of health psychology, which believes that every individual is unique and involves a complex intertwining of biopsychosocial aspects of that individual.

The Biopsychosocial Conceptual Model

Please refer to Figure 3.1, for a simplified outline of the model's concepts. The major aim of this study was to investigate the incidence of depression and anxiety within a sample of people who had ESRD. The literature review described many factors, which may predispose the patient with ESRD to depression and/or anxiety. There were four common themes identified in the literature, these were:

Dialysis Therapy

Most studies found that dialysis is significantly associated with an increased risk of depression. The problems with dialysis therapy included factors such as time commitment; the imposed restrictions in both dietary and fluid intake and lifestyle activities; the effects of the individual being reliant upon long term life-sustaining technology within their own homes; the individual patient and partner’s knowledge regarding the dialysis treatment itself; reliance upon specialist personnel which may be at a distance from the patient’s own locality; life and death decisions for some
patients and their families (e.g. a patient may decide to withdraw from dialysis); the social isolation imposed by the need for regular dialysis treatments, and that imposed by the patients friends and acquaintances; the financial costs involved which are not related to the dialysis equipment in most instances but to those ongoing costs of medications and travel expenses incurred to travel to the dialysis specialist unit; and in some cases the requirement that the partner performs invasive procedures on their patient which can involve injury and discomfort. These unacknowledged costs have been evidenced within clinical nephrology nursing practice.

Perception of Illness

The literature described how the individual’s own perception of their health can impact positively or negatively on their life. How the patient perceives their health is influenced by many factors such as the possible use of denial as a coping mechanism to provide some control over their situation; the need for adaptation to the periods of stable health which are superimposed by acute and possible life threatening episodes of illness; the individual may choose to take a ‘sick role’ and become an invalid which creates great stress on their families; the perceived social stigma of being on dialysis which ultimately leads to social isolation; and the physical limitations and restrictions imposed by the ESRD itself.

The Patient/Partner Dyad

When dialysis commences it is taken into the patient’s family situation and effects all family members, not just the patient. The impact of dialysis is moreso for those families for which home dialysis was the chosen option. Factors which influence the patient/partner dyad are the couple’s ‘lived experience’, that is that environment and family practices into which the dialysis procedure enters. For example, if a couples’
relationship has been poor prior to the commencement of dialysis, clinical experience has shown that this relationship may not improve and may deteriorate further as a result of the higher levels of stress and responsibility that dialysis imposes on the family situation. Other factors which can affect the dyad include the role disruption and possible role reversal that may occur as a result of the patient commencing dialysis; both the patient's and partner's perception of their own and each others health; the social isolation; perceived family support; those imperative lifestyle changes which must occur; and the fear of death in both the patient and their partner.

Role Disruption

Dialysis requires a large on-going time commitment, and the complications, which may occur as a result of dialysis, or ESRD itself impact negatively on a patient’s ability to adhere to a strict employment schedule. As a consequence many dialysis patients are unemployed. Unemployment has many effects such as the loss of financial security and the ability to maintain the individual's standard of living. This will also have a negative affect on the patient’s self-confidence. Many partners have had to become the primary wage earner for their families. This may result in higher levels of stress on the family, as many partners are women who are still expected to perform their usual domestic duties on top of their employment and being the primary carer for a dialysis patient.
Figure 3.1
CONCEPTUAL MODEL

DIALYSIS THERAPY
- Time Commitment
- Imposed Restrictions
- Life-Sustaining Technology
- Dialysis Knowledge
- Specialist Personnel
- Life and Death Decisions
- Social Isolation
- Financial Costs
- Invasive Procedures on Partner

PERCEPTION OF ILLNESS
- Use of Denial
- Acute Illness Episodes
- "Sick Role"
- Reliance upon Complex Technology
- Social Stigma of Dialysis
- Physical Complications of Dialysis

MARITAL DYAD
- Lived Experiences
- Role Disruption
- Dialysis Therapy
- Perception of Illness
- Social Isolation
- Family Support
- Caliber of the Patient/Partner Relationship
- Life-Style Changes
- Fear of Death

ROLE DISRUPTION
- Unemployment
- Dialysis Therapy
- Perception of Illness
- Social Isolation
- Imposed Physical Limitations

PSYCHOLOGICAL REACTIONS
- Depression
- Anxiety
- Positive Coping
CHAPTER FOUR

METHODOLOGY

INTRODUCTION

The methodology for this study was designed to assess the six key variables relevant to the aims and objectives of this study. These variables are: i) depression; ii) anxiety; iii) the dyadic relationship between the patient and their partner; iv) the individual's perception of their illness; v) the severity of renal disease; and vi) evidence of neurological impairment.

Methodology included both quantitative and qualitative techniques. The qualitative data gained from the survey was used to add depth and richness to the data collected using the quantitative methods.

SAMPLE SELECTION

Subjects

All subjects were recruited from a dialysis population within the Illawarra Area Health Service of New South Wales. The potential pool of subjects was 210 (105 patients and 105 partners) who met the criteria for this study based on medical records and information gained from Nephrologists and dialysis nursing staff. The sample included haemodialysis and CAPD patients. The sample size represented the total dialysis population of this single tertiary referral health care facility. The sample was a purposive and convenient sample. A partner was operationalised as the person who assisted the patient with their illness. This assistance may be direct (as in direct
assistance with the dialysis procedure), or indirect (such as being the primary support person). The partner may be a spouse, a parent, a sibling, a relative, or a friend. The selection criteria included the following:

a. Each participant had to have been on dialysis for more than three months. It was hoped at this stage uraemia would be under control and so a possible uraemic effect would not influence responses to the research survey.

b. Each participant had to have good written and spoken English skills. These skills were imperative for the understanding of the survey questions and for the cognitive assessment within some of those questions.

c. Each participant should have no acute medical conditions as they may cause bias in the participant’s responses to the survey questions. The acute medical conditions included all those patients who were in-patients at the time of the survey.

d. Each participant must be of more than 18 years of age to negate possible pubertal change effects in survey responses.

Where possible potential participants were approached personally by the researcher to participate in the study. However there was difficulty in attempting to approach those people on home dialysis programs personally, as they were scattered throughout a very large geographical area. To overcome this difficulty the home dialysis patients were initially approached by mail. This mail recruitment included a letter, which explained the purpose and procedures involved with the study survey (Appendix A). Each potential participant who was on home dialysis was then followed up with a single phone call to ascertain whether they wished to take part in the study. If they chose not to participate no further contact was made, if they chose to participate an appointment was made for the survey interview.
Before the study survey could be implemented, each subject signed a consent form (Appendix A), which stated that they were willing to participate in the study. Each subject was informed of their responsibilities during the survey, and they were also informed that their responses to two questions (the five minute speech samples) would be audiotaped for transcription at a later date. The University of Wollongong’s ethics committee approved the research protocol.

Final Sample Characteristics

Tables 4.1, below give details of the final sample. It was disappointing that so few dialysis patients chose to participate in the survey. Interestingly, the majority of patients who rely on institutional care refused to participate in the survey. This may suggest that this group is a more vulnerable group than the group on home dialysis. The in-centre and self-care dialysis group could be described as having reduced control over their dialysis than that of the home group. However, it was gratifying that a fair percentage of home dialysis patients opted to participate in the survey.

Table 4.1
FINAL SAMPLE CHARACTERISTICS

<table>
<thead>
<tr>
<th>Dialysis Mode</th>
<th>Potential Sample (n=)</th>
<th>Final Sample (n=)</th>
<th>Final Sample as a Percentage of the Potential Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>In-centre haemodialysis</td>
<td>30</td>
<td>3</td>
<td>10%</td>
</tr>
<tr>
<td>Self-care haemodialysis</td>
<td>10</td>
<td>1</td>
<td>10%</td>
</tr>
<tr>
<td>Home Haemodialysis</td>
<td>15</td>
<td>6</td>
<td>40%</td>
</tr>
<tr>
<td>Home CAPD</td>
<td>50</td>
<td>20</td>
<td>36%</td>
</tr>
<tr>
<td>TOTAL</td>
<td>105</td>
<td>30</td>
<td>28.57%</td>
</tr>
</tbody>
</table>

Table 4.2 below gives details of those subjects excluded from the survey and those who chose not to participate in the survey. Those subjects who were excluded due to acute illness were all in-patients and their medical conditions included cardiac events, dialysis access problems, peritonitis, and other non-renal conditions. There were a large number of subjects excluded due to non-English speaking (NES). The
Illawarra area is a large multi-cultural region and therefore a high exclusion rate due to NES was expected. However, this was unfortunate and any future studies should include these people with the use of survey instruments, which have been translated into different languages, and the use of certified health interpreters.

Table 4.2
SUBJECT LOSS FROM POTENTIAL SAMPLE

<table>
<thead>
<tr>
<th>EXCLUSIONS</th>
<th>Subjects (n=)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-English speaking subjects</td>
<td>21</td>
</tr>
<tr>
<td>Acute Illness</td>
<td>5</td>
</tr>
<tr>
<td>Died Prior to survey</td>
<td>5</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>31</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>REFUSALS</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>In-centre haemodialysis</td>
<td>15</td>
</tr>
<tr>
<td>Self-care haemodialysis</td>
<td>9</td>
</tr>
<tr>
<td>Home haemodialysis</td>
<td>4</td>
</tr>
<tr>
<td>Home CAPD</td>
<td>16</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>44</strong></td>
</tr>
</tbody>
</table>

Procedures

Each subject was allocated a code number to ensure confidentiality of information gained during the survey. Data was collected over a period of six months.

Each dyad was interviewed on the same day sequentially (that is the dialysis partner was interviewed first, immediately followed by the patient). Each partner was interviewed separately ensuring that there was no possibility that either the patient or the partner could overhear what was being said to the survey collector. The interview proceeded using a standardised interview schedule (see Table 3.3 for schedule). The researcher who had been trained in the administration of the assessment instruments where training was necessary conducted all interviews. The length of each interview varied, but most were completed within one hour (range was forty-five minutes to one and a half-hours).
Prior to the interview taking place, patient subject's medical records were surveyed. This survey allowed for the extrapolation of specific information needed to complete the individuals medical and dialysis history. The specific information elicited included the patient's: i) haemoglobin, serum urea and creatinine levels at the time of interview; ii) Kt/V being a measure of dialysis adequacy at the time of interview; iii) primary renal diagnosis; iv) renal transplantation history; v) current medications; vi) number of years on dialysis; vii) mode of dialysis therapy; and viii) if there had been any change in renal replacement therapy and the reason for this change. Examination of the patient's medical records also allowed for the assessment of the severity of the individual's renal disease. At each interview, the assessment instruments were administered in a set sequence (Table 4.3) with the order designed to minimise possible bias being transferred from one instrument to another. Pilot testing of different ordered presentations helped to establish the final sequence. The number in the patient and partner column of table 4.3 refers to the order of administration of each instrument. That is 1 means this instrument was administered first, 2 this instrument was administered second, and so on up to 9 being the last instrument which was administered during the survey interview.

**Table 4.3**

**INTERVIEW SEQUENCE SCHEDULES**

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Dialysis Patient</th>
<th>Dialysis Partner</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic Data</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Dialysis/medical history</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Speech Sample</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Beck Depression Inventory (BDI)</td>
<td>4</td>
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<td>Beck Anxiety Index (BAI)</td>
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<td>Dyadic Adjustment Scale (DAS)</td>
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<td>MOS SF-36</td>
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<td>The Color Form Sorting Test (CFST)</td>
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<td>Psychogeriatric Assessment Scale (PAS) - Subject Scales</td>
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The survey interviewer performed demographic data, the Colour Form Sorting Test, and the psychogeriatric assessments of the patients and partners. The BDI, BAI, DAS, and MOS SF36 were all self-report questionnaires. The five minute speech samples were also collected by the survey interviewer, and involved the audiotaping of the patient and the partner's responses to two standard questions (see Appendix C for sample questions). These audiotapes were then transcribed verbatim for thematic analysis.

Pilot Testing

The complete survey was completed on three patient and partner dyads. Two patients were on haemodialysis, and the third was on home CAPD. Once the surveys were completed each dyad was asked if they had any criticism of the survey tools and/or technique. There was no criticism from the individuals, all had found the questionaries easy to interpret and that the time for each survey was adequate. The researcher also found no problems with the administration of the surveys.

The results gained from the pilot study were supported by information within the medical records of these patients. The partners are also referred to in these notes in regard to coping and management of dialysis. Therefore the researcher was confident that the survey was appropriate to meet the objectives of the study.

ASSESSMENT TOOLS

The following survey instruments were chosen to test the variables depression, anxiety, relationships, severity of illness, perception of health, and indications of organic neurological dysfunction. The BDI, BAI, DAS, MOS SF-36, PAS, and CFST are
all quantitative assessment instruments. The five-minute speech sample allows for a qualitative analysis of subject responses.

Quantitative Measures

Demographic Data

This Instrument was designed by the researcher to collect baseline information (Appendix B). The first section asks questions regarding age, gender, marital status, number of living children, languages spoken in the home, years of education, occupation, number of hours worked and annual family income of each subject.

The second section is different for each subject group. The dialysis patient group was asked questions regarding their primary renal disease, dialysis and transplant history, and current medications. The dialysis partner group was asked questions regarding their current medical condition, and current medications.

Content Analysis of Verbal Speech Samples

In order to deepen the understanding of the phenomenological difficulties experienced by the dialysis patient and their partner, transcribed verbal samples were obtained. Previous research has found that verbal samples contain valid indices of the person’s psychological state. The following reviews the research briefly to illustrate the methodology and its application and validity.

In 1976 a study was published which examined 37 schizophrenic and 30 depressed patients, who were living with relatives, and these relatives. The authors (Vaughn and Leff 1976) attempted to replicate and extend the work of Brown, Birley, and
Wing in 1972. This earlier study investigated the rate of relapse in schizophrenic patients and its relationship to expressed emotion by a ‘key’ relative. This expressed emotion during interview was rated on scales which assessed the number of critical comments made about the patient, hostility and emotional over involvement. This was then assessed with the individual patients’ relapse rate. Relapse was defined as type I or type II for the schizophrenic group. Type I involved a change from normal to a schizophrenic state, and type II involved a ‘marked’ exacerbation of schizophrenic symptoms (Vaughn and Leff 1976,128). It was more difficult to define relapse for the depressed group (Vaughn and Leff 1976,128).

Results from the Vaughn and Leff study (1976) showed that a high number of critical comments and expressions of over involvement from relatives supported the higher chance of relapse in the two patient groups within nine months of discharge. Vaughn and Leff (1976,120) go on to discuss that expressed emotion is not the only factor which may indicate the chance of relapse, other factors such as social, clinical and environmental may also influence relapse.

In 1985 Gift, Cole and Wynne described their modification of the Gottschalk-Glesser (1969) standard instructions for speech samples which was not as "...cumbersome..." as that used by Vaughn and Leff. This modification was termed the Wynne-Gift technique. In the Gift et al (1985) article each subject was given a "...standard verbal introduction to the task..." and the verbal response was audio recorded.

Subjects were recruited from parents of 4-year-old children and included 10 divorced or separated mothers and 11 married women. Each woman described the husband (or ex-husband). The transcription of the audio-recordings were then analysed using the Gottschalk rating of hostility out "...which involves assigning a score for expression of anger, dislike, criticism and rejection and assigning a weight
to reflect the intensity of feeling expressed..." (Gottschalk et al 1969).

Gottschalk scaled for direct and indirect statements of hostility and has a reported inter-rater reliability of $r=0.92$ with these scales (Gift et al 1988).

Results supported the author's hypothesis that the divorced and separated group would have more hostility than the married group. Therefore the results support the validity of the modified speech sample as designed by Wynne and Gift. Gift et al (1988,209) further point out, ... "An important practical issue with the use of the Wynne-Gift procedure is that of maintaining a rapport with the subject."

Gottschalk, Falloon, Marder, Lebell, Gift, and Wynne (1988) further used the Wynne-Gift modified speech sample to predict the relapse of schizophrenic patients. Three patient samples were chosen from different facilities and relatives of these patients were interviewed when the patient had clinically stabilised. Each speech sample was analysed for expressions of expressed hostility towards the patient. The results of this study further supported previous findings (Vaughn and Leff 1976; Gift et al 1988) in that analysis of 5-minute speech samples for expressions of hostility can predict possible relapse in the schizophrenic patient.

Viney (in Gottschalk, Lolas, and Viney 1986, 70-71) discusses problems and limitations with the use of content analysis of speech samples. Content analysis: i) is limited to speech samples; ii) does not deal with the functional aspects of language; iii) can only be used if the "concept is not precisely defined"; iv) should not be used to analyse data if it is assumed that the subjects' language may not provide viable data (eg. in the cases of intellectual disability or the use of a non-native language).

Lebovits and Holland (in Gottschalk et al 1986, 141-142), also support the reliability and validity of the 5 minute speech sample in persons with different medical disorders (cancer, coronary artery disease, dermatological diseases and persons with
hypothesis). Also the speech samples do not have some of the problems that are inherent in self-reports and observer rated measures. "Psychological defence mechanisms, such as denial or rationalisation, mobilised by illness may distort the patient’s reports of their states" (Lebovits and Holland 1986,134). With the observer rated measures raters must be trained in all aspects of the measure which takes time and money, plus the inter-rater reliability has to be established prior to the use of the particular measure (Lebovits and Holland 1986,134). The major problem with speech samples is the anxiety associated with the use of a tape recorder, which may modify the subject’s mood and so effect the verbal sample (Lebovits and Holland 1986,142). Despite these limitations, the previously established predictive validity of this technique justified the collection of speech samples to strengthen the quantitative data with a qualitative measure.

The Beck Depression Inventory

The Beck Depression Inventory (BDI) is a self-report questionnaire, (or can be administered by an interviewer), which has 21 items. Each item is rated on a scale of 0 - 3, with 0 being the least severe and 3 being the most severe. The total score range is from 0-63. The BDI was designed by Beck around 1961, and was modified in 1971. Development of the BDI was based on clinically observed manifestations of depression. The cut off scores for the BDI are: i) no or minimal depression <10; ii) mild to moderate depression 10-18; iii) moderate to severe depression 19-29; and iv) severe depression 30-63 (Beck, Steer, and Garbin 1988, 79-80). Beck et al (1988, 80)) cite BDI mean scores for minimal, mild, moderate, and severe depression as 10.9 (s.d.=8.1), 18.7 (S.D. =10.2), 25.4 (s.d.=9.6), and 30.0 (s.d.=10.4) respectively from Beck's earlier work in 1967.
Beck et al (1988,83) reviewed 25 published articles covering the period from 1961 to 1986 in which the internal consistency of the BDI was assessed. These articles reported co-efficient alphas from .73 - .95 that are high. The 1988 article by Beck et al also reports good stability of the BDI over a one-week period with psychiatric and non-psychiatric patients. This article further reports on a very acceptable validity in both psychiatric and non-psychiatric patients. ...“The BDI...also demonstrates a strong positive relationship with four well researched instruments measuring depression: a) the HRSD. B) the Zung; c) the MMPI-D scale; and d) the MAACL-D scale”... (Beck et al 1988,95).

Items 14-21 on the BDI are somatic items. Each of these items can be associated with the clinical consequences of end stage renal disease. Studies, which have investigated depression within medically ill populations, have found difficulties with these somatic items. It could not really be demonstrated that whether the patient who had a high BDI score was cognitively depressed, or whether the high score was related to their medical illness.

Beck and Steer (1987) report in the BDI manual that two subscales can be used. Items 1-13 represent “a cognitive-affective subscale of estimating depression in persons whose vegetative and somatic symptoms might over estimate the severity of their depressions.” Items 14-21 measure somatic and performance complaints. Beck and Steer (1987) report “that a score of >10 on the cognitive-affective subscale was indicative of moderate depression.”

Cravin, Rodin, and Littlefield (1988) commenced a study whose main objective was to compare the BDI with the DSM-III (from the American Psychiatric Association, which is a diagnostic and statistical manual of mental disorders) in renal dialysis patients. The sample consisted of 198 patients, and 99 of these were included in the
study. Each subject was interviewed using the Diagnostic Interview Schedule (from which the DSM-III was derived. The cut off points were as reported by Beck et al in 1961 for a normal population. This cut off point was lower than that again reported by Beck et al in 1988 for an affective disorder. The cut off scores for the BDI used by Craven et al (1988,368) were: 0-9 (non-depressed); 10-15 (mildly depressed); 16-23 (moderately depressed); ≥ 24 (severely depressed). The overall finding was that the BDI (all 21 items) is a useful screening tool with a cut off point of ≥ 15 for depression.

Beck et al (1961) reported agreements between the BDI and psychiatrists on 300 patients to be 56%, and the BDI is able to distinguish depression from anxiety. Shulman et al (1989,953) disagrees, they feel that this differentiation was “imprecise”. Bowling (1995,80), in her review of disease specific quality of life measurement scales that the BDI has good “psychometric properties [even though] most of the tests have been done on psychiatric populations.”

Shulman, Price, and Spinelli (1989,953) argue that there has been much criticisms of depression instruments which have somatic items. So in their study they corrected for this. Their results showed an association between the BDI score and survival rates in 64 haemodialysis patients. Another interesting finding within their sample was that “...the main validity of the BDI was its high correlation with a chronic dysphoric state present for years or months without remission in patients previously well before dialysing”... (1989,953).

In conclusion the BDI has good reliability and validity. In addition to the full BDI scale score, a subscale CDI (Cognitive Depression Index) score can be derived which is particularly useful for distinguishing cognitive depression in patients with ESRD.
The Beck Anxiety Index (BAI)

Beck, Epstein, Brown and Steer developed the Beck Anxiety Index (BAI) in 1988. The BAI can be self-administered or administered by an interviewer. The BAI questionnaire consists of 21 items to assess the symptoms associated with anxiety. The BAI items were developed from three other questionaries. The Anxiety Check Test (ACT), the FDR checklist, and the situational anxiety check list (SAC) (Beck 1990,1).

Beck and his colleagues sampled 810 adult outpatients, who had completed the ACI, the FDR and the SAC. This resulted in the identification of 86 symptoms of anxiety. Of these, some items were immediately discarded because they were the same or similar to another, and some discarded following a low factor analysis. This attrition of items resulted in 37 items, which were further assessed on a sample of 116 adult outpatients. Following a further factor analysis 21 symptoms were identified as being important indicators of anxiety. It is these 21 items which comprise the BAI (Beck 1990,1-3).

These 21 items are rated on a four-point scale. The lowest possible being (0) (it did not bother me much), to 3 (it bothered me severely, I could barely stand it). The BAI total score range is similar to the BDI of 0-63. Severity rating of anxiety is scored as:

i) 0-9 indicates a normal level of anxiety; ii) 10-18 indicates mild to moderate anxiety; iii) 19-29 indicates moderate to severe anxiety; and iv) 30-63 indicates a severe anxiety state. Beck in his BAI manual (1990,5) points out that sensitivity and specificity for score ranges has not been conclusively assessed. He goes on to say that anxiety scores for women may be higher than for men (1990,5). Beck also warns that as the BAI has many somatic items included that a high BAI score consisting mainly of somatic items may indicate an underlying medical condition.
Beck and Epstein (1988, cited in Beck 1990,7) had a final sample of 160 psychiatric outpatients on which the BAI was tested. The results from this was a Cronbach coefficient alpha = .92 (Beck 1990,8). In the BAI manual (Beck 1990) presents results from a sample of 393 psychiatric outpatients, with various disorders. Mean scores, SD, and r for each item of the BAI are reported in the BAI manual and all were proven to have content validity as they corresponded to the symptom criteria presented in the DSM-III-R (....). Concurrent validity was also demonstrated by being significantly related to other anxiety measures (both self-report and clinical assessment) (Beck 1990, 13). Construct validity is reported by the BAI having a significant relationship to the BDI (r=. 61, p < .001) (Beck 1990, 14-14).

Factorial analysis of the BAI revealed two highly correlated dimensions the first representing somatic aspects of anxiety (numbness, feeling hot, shaky and sweating), and secondly panic related aspects of anxiety (fear of the worst, terrified, fear of losing control) (Beck 1990,15-16). On further investigation four subclusters were described those of neurophysiological, subjective, panic, and autonomic symptoms of anxiety. Beck reports that further research needs to be carried out to investigate the reliability of these cluster groupings (Beck 1990, 18).

Taking the limitations of the BAI into consideration, the BAI was selected as a quick and valid measure of clinical anxiety.

The Dyadic Adjustment Scale (DAS)

In 1976 Spanier published his article in which he describes the development of a new scale which measures overall dyadic adjustment. Dyadic adjustment refers to the concept of the marital relationship. Spanier (1976,16) says that“...Marital or dyadic adjustment may be viewed in two distinct ways - as a process or as a qualitative
evaluation of a state..." Spanier discusses that the marital relationship is constantly changing over time and therefore can be viewed as a process. So any measure of the relationship can only assess a particular marital dyad at the particular time of assessment.

Following a literature review Spanier (1976,17) reports that the marital relationship has been studied since 1929. He goes on to discuss that previous developed measures of the marital dyad had problems in that: i) there were doubts about the way the validity and reliability were reported; ii) they had no definite conceptual plan to support the development of the measures; and iii) none of them had been designed for use with other dyads.

The procedure to develop the Spanier scale was involved and included a review of all measures of marital adjustment to obtain valid items (those that were concerned with relationships). Following this a questionnaire of 200 items were distributed to a sample of 218 married persons and 400 persons who had gained a divorce within the preceding twelve months. 109 and 90 completed questionnaires were returned respectively. There were also a small number of unmarried co-habitating couples included, the exact number was not reported.

The scale, which evolved from the above sampling contained 32 items and can be self-administered or can be adapted to interview. Reliability was assessed using only the married sample. The scale was acceptable for: i) content validity; ii) criterion related validity (the divorced sample had a significant difference from the married sample at a p<0.001) using a t-test, the mean scores for the married sample was 114.8, and 70.7 for the divorced sample; iii) and construct validity, when the DAS was compared to the Locke-Wallace Marital Adjustment Scale, which showed a correlation of .86 among the married sample and .88 among the divorced sample at a p < 0.001; and
iv) after factor analysis of each item (Spanier 1976,23). Spanier did not report findings amongst the small sample of unmarried respondents.

Reliability was established by use of Cronbach's Co-efficient Alpha statistic which was .96 for the whole scale, with the subscales of consensus, satisfaction, cohesion, and affection expressed being .90, .94, .86, .73 respectively (Spanier 1976,24).

In 1982 two Australian Universities collaborated to conduct a study to replicate the 1976 Spanier study. Sharpley and Cross (1982) selected a sample of 95 married persons (58 women and 37 men) who completed the DAS. The mean score was 108.5 (S.D. 19.7), which is comparable to that reported by Spanier of 101.5 over all samples (1976,23).

Sharpley and Cross analysed their data in three steps: i) discriminate analysis; ii) item analysis; and iii) factor analysis. They used the mean score as a cut off point as Spanier had provided none. Sharpley and Cross found that all items discriminated well but especially items 8, 10, 11, 25, 27, and 28 (1982,740). Overall reliability was reproduced of .96. They concluded "...most of the original items on the DAS are unnecessary...Researchers can obtain almost as confident classification by use of... 8, 10, 11, 25, 27, 28...[and]...the suggestion by Spanier (1976,21-22) that 4 subscales may be drawn from the DAS is not verified by the present study"...

In this survey the modified DAS, as suggested by Sharpley and Cross' Australian analysis was used. That is only items number 8, 10, 11, 25, 27, and 28 of the original Spanier DAS were used. Two extra items were included to assess the patients' and partners' perceived criticism of each other.
The Psychological Effects of Dialysis on the Patient and their Partner
Chapter Four - Methodology

The scale has good validity at separating poor from good dyadic adjustment and has been used to study the quality of life of spouses of CAPD patients (Dunn, Lewis, Bonner, and Meize-Grochowski 1994). This study found that only 28% of subjects scored above average and 38% scored below average on the DAS (p.242).

The Medical Outcomes Study - Short Form 36 (MOS SF 36)

The MOS:SF36 is described as a generic measure of quality of life (Bowling 1995,281) which was derived from The Rand Corporation’s Health Insurance Study in the United States of America. This study investigated health outcomes of 8,000 adults aged 14-61 years who had been randomly assigned to differing insurance plans (Bowling 1995,281). The MOS SF 36 covers the categories “...physical functioning (10 items); social functioning (2 items); role limitations due to physical problems (4 items); role limitations due to emotional problems (3 items); mental health (5 items); energy/irritability (4 items); pain (2 items); and general health perceptions (5 items)...” (Bowling 1995,282). Items are scored on a scale from 0 (poor health) to 3 (good health).

The MOS SF 36 is increasing in use world wide and Ware et al (1992) reported that the 5 items on mental health have “…particularly impressive validity (r=0.92-0.95) with the full mental health inventory...” Brazier et al (1992,164) reported that the MOS SF 36 had good construct validity and that it was brief and easy to use. Brazier et al (1992) supported the findings of Ware et al (1992) following a postal survey of 1980 persons using the MOS:SF36. Jenkinson, Coulter, and Wright (1993) further assessed the MOS:SF36 on 13,042 randomly selected subjects aged 18-64 years and they reported a 72% response rate. Their results gave an internal consistency of ≥ .76α (Cronbach’s alpha statistic). This is an acceptable level as Jenkinson et al (1993)
cites Stewart et al (1988) "...that in practice well used scales should have $\alpha$ values > 0.8...". The Jenkinson et al (1993) study provides normative data (means and S.D.) and also provides evidence that those subjects who had long standing illness had much lower scores on the MOS SF 36 than those subjects who did not.

Brazier et al (1992) reported a lower response rate to the MOS:SF36 in the >65 year age group (posted survey rather than interview) but this has not been reported elsewhere.

Bowling (1995,284) cites Anderson et al (1993) as expressing concern regarding a 'ceiling effect' of the MOS:SF36, and that the concentration on mobility in the physical functioning set of items, may exclude changes in domestic chores which may be of importance to the individual. Bowling goes on to discuss that the MOS SF 36 needs further assessment "...for its discriminatory power between different disease and treatment groups..." (1995,284).

Garrett et al (1993,1440) also assessed the MOS SF 36 and supported previous cited studies (Stewart et al 1988; Jenkinson et al 1993; Brazier et al 1992; Bowling 1995) that the MOS SF 36 is a valid and reliable tool for health status but that its "...sensitivity to health status over time must also be tested...".

McCullum (1995) assessed the MOS:SF36 by using an Australian sample from the National Heart Foundation Risk Factor Prevalence Survey in 1989 and they were retested in 1992. 555 subjects agreed to complete a one-hour interview. McCullum also gives means, S.D., and Cronbach alpha scores for his sample. He goes on to state that the "...SF-36 has been successfully validated in Australia given its performance in the United States and the United Kingdom ... and has the potential to be used as a health outcome indicator...".
Merkus et al (1997) conducted a multi-centre study on the quality of life of ESRD patients who had just commenced dialysis using the MOS SF 36. This study consisted of 226 subjects (120 haemodialysis and 106 peritoneal dialysis). The results were then compared to the general Dutch population scores on the MOS SF 36. The age range of subjects was 18-86 years. The results showed that both the haemodialysis and peritoneal dialysis patients perceived their health as much lower than the general population (1997,587). They further reported that co-morbidity factors such as cardiovascular disease and diabetes mellitus had lower quality of life scores; as did those subjects with a lower glomerular filtration rate. The authors also pointed out that the mean age of their sample was 44 years which was an issue of concern as the MOS:SF36 has a negative correlation with age. To check this they compared the total scores of the total sample with a subgroup within the sample, that is those aged 55-64 years (n=140) and both those subjects on haemodialysis and peritoneal dialysis had lower MOS SF 36 scores than the general population.

Due to its established validity the SF 36 was chosen for use in this study as a good measure of the impact of ESRD on quality of life and its proven ability to distinguish the physical and mental health effects on the quality of life.

The Psychogeriatric Assessment Scales (PAS)

The Psychogeriatric Assessment Scales (PAS) were developed by two Australians Jorm and Mackinnon in 1994. The PAS has been developed to assess the clinical alteration of depression and dementia in the elderly. It consists of two parts: i) the first is an interview schedule for the person with the suspected dementia/depression (the subject); and ii) the second is an interview schedule for an ‘informant’. This informant is most likely a spouse, close relative or friend. Both these interviews allow
...“different perspectives on the subject’s functioning.”... (Jorm and Mackinnon 1994,3).

The subject interview consists of three scales: i) a stroke scale (6 items); ii) a depression scale (12 items); and iii) a cognitive impairment scale (9 items). The ‘informant interview also consists of three scales: i) stroke (6 items); ii) cognitive decline (10 items); and iii) behaviour change of subject scale (15 items). Each scale can be independent that is only one aspect of the scale may be used to assess one parameter - for example cognitive decline. Each item of the scale can be scored either 0 or 1. Scoring is simple and each individual subject’s score is compared to the population norms. There is another possible score for each item and that is a query (?) which is for an unknown. This factor on any PAS makes scoring a little more difficult as there is a correction factor, which has to be computed with overall raw score. The reference point for the PAS is people aged ≥ 70 (Mackinnon et al 1994,13). Each subject’s score is then plotted on a percentile chart and the higher the percentile rank than the more impaired that person is. On the percentile charts there is criterion set where “…most diagnosed cases lie…” (Mackinnon et al 1994,17).

Mackinnon et al (1994,14) caution that although the PAS can be used in younger people their degree of impairment may be greater if compared with their own age group.

They also discuss the impact of poor education in subjects and emotional distress of the ‘informants. Poor education may give a falsely high score on the cognitive scales.
It can be expected that persons with dementia will have higher scores on: i) cognitive impairment and decline; and ii) behavioural changes than persons with depression (Jorm and Mackinnon 1994,19).

The scales developed by Jorm and Mackinnon cover the "...clinical domains of dementia and depression as defined by the ICD-10 and the DSM-111 criteria..." (Jorm et al 1995,448). The scales were based on the Canberra Interview for the Elderly (CIE).

Reliability of the PAS scales were assessed using Cronbach’s Alpha and test-retest coefficients and were evaluated at the P < 0.01 level. Results of this sample support good measure of reliability especially in regard to test-retest co-efficients of .68 -.81 for subject scales in Sydney and Geneva, and .83 -.97 for informant scales in Sydney and Geneva. Also good validity was reported using Receiver Operating Characteristics (ROCS), and were than compared to the ICD-10 and DSM-111-R criteria for the diagnosis of depression and dementia.

The PAS cognitive impairment and behavioural subsets were used for this study due to its reported validity and being able to measure cognitive decline and behavioural changes which are associated with dementia.

The Color Form Sorting Test (CFST)

The Color Form Sorting Test (CFST) is also called the Weigl’s Test or the Weigl-Goldstein-Scheerer Color Form Sorting Test. This test is performed using 12 objects. These objects consist of 4 squares, 4 triangles, and 4 circles with each shape group consisting of 4 primary colours—1 red, 1 blue, 1 yellow and 1 green. Each subject
being tested is asked to sort these objects and once they have finished the task, they are then asked to sort the objects again but in a different way. At the completion of each separate task the subject is asked why they sorted the objects as they did. Deutsch-Lezak (1995, 619) reports that "...inability to sort is rarely seen in persons whose premorbid functioning was much above borderline defective...[and]...Inability to shift is evidence of impaired mental functioning in persons who were operating at a better than dull normal level to begin with..."

Grewal (1988, 569) reported that the CFST could discriminate very well between dementia and depressed patients. Grewal (1988) further conducted a study to assess whether the CFST was sensitive to differences among brain damaged and demented individuals. He used two groups, firstly demented patients (n=48) with a mean age of 74.5 years, and secondly a group of depressed patients (n=48) with a mean age of 72.25 years. The CFST was administered as was the Organic Integrity Test devised by Tien (Grewal, 1988, 569). The results showed that the CFST could significantly discriminate between mild and severe dementia but was not sensitive enough to discriminate between moderate and severe dementia or mild to moderate depression in either sample groups.

In 1992 des Rosiers reported that the "CFST provides a quick means to evaluate abstract thinking in which tokens must be arranged according to form and/or colour and early reports using CFST in Alzheimer’s Disease patients commented on their considerable difficulties in shifting from color to form sorting ...[this is also supported by Abas et al 1990]...” (314). The brain’s ability to identify colour is less complex than the ability to identify shape (Isenberg et al 1990). Des Rosiers supports that the CFST is a sensitive test but has questions about its specificity and suggest that a third level such as size or number should be included to increase the discrimination.
between dementia and depression (1992,315). Depressives have little or no difficulty in sorting by colour or shape.

The scale was included to exclude subjects with undiagnosed early dementia, whose scores would prejudice true estimates of depression for this population.

The End Stage Renal Disease Severity Index (ESRD-SI)

The End Stage Renal Disease Severity Index (ESRD-SI) was developed by Craven, Littlefield, Rodin, and Murray (1991), in response to a perceived need for an assessment instrument which would assess the severity of renal disease and which did not have a cross over of psychosocial issues within it. There are three components of disease severity, which are measured commonly, although not clearly distinguished from each other: physiological severity; functional severity; and burden of illness (Stein et al 1987 cited in Craven et al 1991,237). The most common measures of renal disease severity include hospital admission rates/days, and the physiological parameters of renal disease, which include haematology and biochemical information. Craven (1991,238) goes on to say that didactic measures such as hospital admissions and physical complaints can be greatly influenced by the somatisation of some psychological dysfunction. He also says that many measures of renal disease severity do not account for many other illnesses, which can affect the person with renal disease such as diabetes mellitus, and cardiovascular disease. As Santiago and Charzan (1989) point out, "... Death in dialysis patients most commonly results from concurrent illness..." (Santiago and Charzan,1989). Research has also shown that there are predictors of mortality, which have proven to be statistically significant. "These include physical comorbidity, demographic variables (age and race) and psychosocial variables (eg. depression)" (Griffin et al 1995,189).
The ESRD-SI comprises of ten disease categories which can commonly be found in those patients with End Stage Renal Disease (ESRD). The categories are:

- cardiovascular disease;
- cerebrovascular disease;
- peripheral vascular disease;
- peripheral neuropathy;
- bone disease;
- respiratory disease;
- visual impairment;
- autonomic neuropathy and gastrointestinal disease;
- access and dialysis events;
- diabetes mellitus;
- and an 'other' category. “These illnesses were chosen for inclusion ... as they are the most common complications and concurrent conditions found in ESRD and are each major determinants of morbidity and mortality.” (Craven et al 1991,238). These statements are supported by the Australian experience (Disney 1996). Each disease category is assessed on a six point Likert scale from absent (0) to severe (9 or 10). Each point on the scale has qualifying criteria to assist the rater assess the severity of ESRD and does not include psychosocial factors. The criteria for the scale are defined by: 1-3 for biochemical or mild indications of disease; 4-6 for moderately severe physical signs, handicap or prognosis; 7-8 for severe physical handicap or prognosis; and 9-10 for an imminently lethal condition (Craven et al 1991,238).

Each disease category has a different range of scores, and the total overall score is the total severity index (Craven et al 1991,238). Craven et al (1991) investigated two sample groups to assess the validity and reliability of the ESRD-SI. The first group consisting of in-centre dialysis and intermittent peritoneal dialysis, were used to assess inter-rater reliability. One quarter of this group were included in the sample which looked at the validity of the ESRD-SI. In this second sample, which consisted of in-centre haemodialysis, intermittent peritoneal dialysis and continuous ambulatory peritoneal dialysis, construct and predictive validity were investigated. Craven et al (1991,239) reported the following results: i) the overall inter-rater reliability was $r = 0.92$ ($P<0.01$) over a one week period; ii) the overall test-retest correlation was $0.923$ ($P<0.001$) with a mean difference of $0.34$ ($P = 0.470$); iii) the second sample
was further analysed to reveal the mean ESRD-SI was 10.2 with a S.D. = 9.59. A Tukey Multiple Comparison Test was performed at 0.05 probability level to identify groups with a significant F value. The groups with higher F scores were i) older, ii) unemployed due to medical disability; iii) those on intermittent peritoneal dialysis (P = 0.002), with diabetes mellitus (P = 0.001) or who died within 6 months of the initial rating.

In 1995 Griffin et al published a study which investigated the validity of the ESRD-SI in haemodialysis and CAPD patients in a total sample of 82 (35 HD, and 47 CAPD). They compared the ESRD-SI with the three aspects of disease, which are most commonly investigated. These are: the physiological indications of severity; functional status; and the psychological impact of the disease. Their overall finding suggested that the ESRD-SI “is a valuable research tool with construct validity” (1995, 189)

These results support the use of the ESRD-SI as a reliable, valid, and objective assessment of the physiological severity of renal disease to the exclusion of any psychosocial bias. Craven et al (1991, 329-240) report that the ESRD-SI is sensitive to factors associated with the risk of increased morbidity and mortality and includes advanced age, concurrent diabetes, unemployment for medical reasons, intermittent peritoneal dialysis; and nearness to death.

The ESRD-SI was included in this study to provide an unbiased (no psychological factors included) estimate of the severity of renal disease.
CHAPTER FIVE

QUANTITATIVE RESULTS

Fifty-two people consented to participate in the study. There were 22 dyads (patient and partner) and a further 8 patients who either did not have a partner, or their partner was unwilling to participate in the research.

DEMOGRAPHICS

General Demographics

Table 5.1 presents the demographic details of both the patient and partner groups.

Table 5.1
DEMOGRAPHIC DETAILS OF STUDY GROUP

<table>
<thead>
<tr>
<th></th>
<th>Patients (n=30)</th>
<th>Partners (n=22)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age (years)</td>
<td>62.07 (SD 11.69)</td>
<td>62.00 (SD 11.4)</td>
</tr>
<tr>
<td>Gender mix</td>
<td>Males 53.33% (n=16)</td>
<td>36.36% (n=8)</td>
</tr>
<tr>
<td></td>
<td>Females 46.66% (n=14)</td>
<td>63.64% (n=14)</td>
</tr>
<tr>
<td>Marital State</td>
<td>Single 3.33% (n=1)</td>
<td>5.55% (n=1)</td>
</tr>
<tr>
<td></td>
<td>Married 80% (n=24)</td>
<td>90.91% (n=20)</td>
</tr>
<tr>
<td></td>
<td>Widowed 6.66% (n=2)</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>Divorced 10% (n=3)</td>
<td>5.55% (n=1)</td>
</tr>
<tr>
<td>Language spoken at home</td>
<td>English</td>
<td>English</td>
</tr>
<tr>
<td>Mean number of children</td>
<td>2.5 (SD 1.4)</td>
<td>2.77 (SD 1.23)</td>
</tr>
<tr>
<td>Education and Qualifications</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean years of school education</td>
<td>7.24 (SD 1.39)</td>
<td>8.95 (SD 1.36)</td>
</tr>
<tr>
<td>No High School</td>
<td>30% (n=9)</td>
<td>5.55% (n=1)</td>
</tr>
<tr>
<td>Some High School</td>
<td>6.66% (n=2)</td>
<td>18.18% (n=4)</td>
</tr>
<tr>
<td>Intermediate/School Certificate</td>
<td>50% (n=15)</td>
<td>68.18% (n=15)</td>
</tr>
<tr>
<td>Matriculation/H.S.C.</td>
<td>13.33% (n=4)</td>
<td>9.09% (n=2)</td>
</tr>
<tr>
<td>Trade Qualification</td>
<td>30% (n=9)</td>
<td>22.73% (n=5)</td>
</tr>
<tr>
<td>Tertiary Qualification</td>
<td>10% (n=3)</td>
<td>9.09% (n=2)</td>
</tr>
<tr>
<td>Occupation</td>
<td>Unskilled 60% (n=18)</td>
<td>68% (n=15)</td>
</tr>
<tr>
<td></td>
<td>Trade 26.66% (n=8)</td>
<td>18.18% (n=4)</td>
</tr>
<tr>
<td></td>
<td>Professional 6.66% (n=2)</td>
<td>9.0% (n=2)</td>
</tr>
<tr>
<td></td>
<td>Never Employed 6.66% (n=2)</td>
<td>5.55% (n=1)</td>
</tr>
<tr>
<td>Hours worked per week</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No work</td>
<td>93.33% (n=28)</td>
<td>77.27% (n=17)</td>
</tr>
<tr>
<td>Full time (38 hrs./week)</td>
<td>3.33% (n=1)</td>
<td>5.53% (n=1)</td>
</tr>
<tr>
<td>Part-time work</td>
<td>N/A</td>
<td>13.64% (n=3)</td>
</tr>
<tr>
<td>Volunteer work</td>
<td>3.33% (n=1)</td>
<td>0% (n=0)</td>
</tr>
<tr>
<td>Annual Family Income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>$0 - 15,000</td>
<td>80% (n=24)</td>
<td>77.27% (n=17)</td>
</tr>
<tr>
<td>$16 - 30,000</td>
<td>13.33% (n=4)</td>
<td>18.18% (n=4)</td>
</tr>
<tr>
<td>$46 - 60,000</td>
<td>6.66% (n=2)</td>
<td>5.55% (n=1)</td>
</tr>
</tbody>
</table>
The mean age for both groups is very similar. When subjects whose age was > 60 years were selected out, the mean age increased to 67.36 (n=22) and 67.93 (n=17) for patients and partners respectively. This older age group accounts for 75% of the total study sample (n=52).

Figure 5.1
DISTRIBUTION OF ALL SUBJECTS AGES

Figure 5.1 above, illustrates the distribution of ages for all subjects, it is not a normal distribution, with the greatest frequency of ages being above the mean age for both groups which was 62 years (the median age was 62 years).

Most subjects were married, and the partner group had a slightly higher mean number of children, as some partners had been married twice.

Most subjects (n=30) from both study groups attained the school educational level of 'Intermediate' (year 9) or School Certificate (year 10). Most subjects (n=33) were
employed in unskilled positions currently or prior to retirement. Most subjects (n=45) were not employed, this category included those subjects who were retired and who undertook home duties. There was only one patient employed on a full time basis.

The annual family income of most subjects (n=41) is equal to that of an annual pension (aged pension, unemployment/sickness benefits) payment.

Dialysis Demographics

Table 5.2 summarises dialysis demographics.

### Table 5.2

<table>
<thead>
<tr>
<th>PATIENT GROUP (n=30) DIALYSIS DEMOGRAPHICS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Primary Renal Disease:</td>
</tr>
<tr>
<td>Glomerulonephritis</td>
</tr>
<tr>
<td>Diabetic Nephropathy</td>
</tr>
<tr>
<td>Analgesic Nephropathy</td>
</tr>
<tr>
<td>Other causes</td>
</tr>
<tr>
<td>2. Mean number of months on Dialysis</td>
</tr>
<tr>
<td>3. Type of Dialysis Therapy</td>
</tr>
<tr>
<td>Haemodialysis</td>
</tr>
<tr>
<td>Home Haemodialysis</td>
</tr>
<tr>
<td>In-Centre Haemodialysis</td>
</tr>
<tr>
<td>Self-Care Haemodialysis</td>
</tr>
<tr>
<td>Peritoneal Dialysis</td>
</tr>
<tr>
<td>C.A.P.D.</td>
</tr>
<tr>
<td>5. Biochemistry and Haematology</td>
</tr>
<tr>
<td>Mean Haemoglobin</td>
</tr>
<tr>
<td>Mean Urea</td>
</tr>
<tr>
<td>Mean Creatinine</td>
</tr>
</tbody>
</table>

The incidence of primary renal disease found in the study group was consistent with Australian statistics as evidenced in the ANZData report (Disney 1996). Diabetes Mellitus was the second most common cause of ESRD in the study group. The mean time on dialysis was equal to 2.9 years with a range of .5 – 10 years. Home peritoneal dialysis was the most common form of dialysis therapy within the study group.

Biochemistry and haematology is within clinically acceptable levels for ESRD, with a cautionary statement that it is unknown whether serum urea and creatinine results for each subject, were pre or post dialysis. If the specimens were taken after dialysis
than the results from this study may be suggesting a better result than there may actually be. Or it may suggest that each subject is being dialysed relatively well.

Some patients had changed treatment modalities from CAPD to HD prior to the survey period. Most changes resulted from peritonitis.

Unfortunately dialysis adequacy (Kt/v) results were unavailable for most patient subjects within the survey sample.

The partner group results showed that 27% had no medical conditions, whilst 73% did. Medical conditions reported included arthritis, low back pain, hypertension, cancer, cardiac disease, asthma, diabetes mellitus, thyroid dysfunction, and chronic fatigue syndrome. Some partners had more than one medical condition. All medical conditions were present prior to the commencement of dialysis.

All patients were taking multiple medications as is usual with patients with ESKD. These medications included cardiac glycosides, anti-arrhythmics, cholesterol lowering agents, anti-hypertensives, anticoagulants, erythropoetin, phosphate binding agents (Calcium, Magnesium and Aluminium based preparations, nightly sedation, anti-cholinergics, multi-vitamin preparations, and other disease specific medications such as ventolin puffers and prednisone for asthma for example.

Medications were being taken by 63.63% of partners. Medications being taken was in many cases polypharmacy, and included the drug groups non-steroidal anti-inflammatories, anti-hypertensives, anti-arrhythmics, insulin, bronchodilators, thyroid hormones, anti-coagulants, diuretics, and in one case chemotherapy.
Study Variables

Eight measuring instruments were used to assess two independent variables, and four dependent variables. The independent variables were depression and anxiety. The dependent variables were severity of renal disease and neurological impairment (patient group only), the relationship between the patient and their partner, and the perception of individual health in both patient and partner groups. Table 5.3 lists the measures, which were used for the studied variables with the mean scores and standard deviations from the study groups.

Table 5.3
MEAN SCORES AND STANDARD DEVIATIONS FOR MEASURES USED TO ASSESS VARIABLES IN THE STUDY GROUPS

<table>
<thead>
<tr>
<th>Measures</th>
<th>Patients (n=29)</th>
<th>Partners (n=22)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Independent Variables</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Beck Depression Inventory</td>
<td>15.13</td>
<td>7.75</td>
</tr>
<tr>
<td>Cognitive Depression Inventory</td>
<td>5.2</td>
<td>2.5</td>
</tr>
<tr>
<td>Beck Anxiety Index</td>
<td>10.03</td>
<td>3.71</td>
</tr>
<tr>
<td><strong>Dependent Variables</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>End Stage Renal Disease Severity Index</td>
<td>25.03</td>
<td>N/A</td>
</tr>
<tr>
<td>Psychogeriatric Assessment Scale</td>
<td>1.7 c</td>
<td>N/A</td>
</tr>
<tr>
<td>Color Form Sorting Test</td>
<td>P*</td>
<td>N/A</td>
</tr>
<tr>
<td>Dyadic Adjustment Scale (Items 1-6)</td>
<td>3.51</td>
<td>3.55</td>
</tr>
<tr>
<td>Medical Outcomes Study SF-36</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical functioning</td>
<td>31.12</td>
<td>70.45</td>
</tr>
<tr>
<td>Role-Physical</td>
<td>23.33</td>
<td>68.18</td>
</tr>
<tr>
<td>Bodily pain</td>
<td>53.23</td>
<td>67.95</td>
</tr>
<tr>
<td>General Health</td>
<td>29.87</td>
<td>70.41</td>
</tr>
<tr>
<td>Vitality</td>
<td>36.50</td>
<td>61.36</td>
</tr>
<tr>
<td>Social functioning</td>
<td>57.92</td>
<td>79.55</td>
</tr>
<tr>
<td>Role-Emotional</td>
<td>66.66</td>
<td>75.76</td>
</tr>
<tr>
<td>Mental Health</td>
<td>62.93</td>
<td>78.91</td>
</tr>
</tbody>
</table>

Note
1. * Denotes that this is the mean score and standard deviation for the cognitive set (memory and concentration) of the PAS.
2. B Denotes that this is the mean score and standard deviation for the behavioural change set of the PAS.
3. * Denotes that this measure had no numerical score, only a pass (P) or a fail (F).
Neurological Impairment

The Psychogeriatric Assessment Scale

Two sub-sets within the total PAS were used. These sub-sets were the Cognitive set which assessed memory and concentration, and the behaviour set which assessed behavioural change. The subject completed the cognitive set of questions themselves. The patient’s partner completed the behavioural change questions. The partners were not assessed. There were only two scores possible for each item on both subsets, zero or one. A score of one signifies impairment in cognition or a change in behaviour. There is a third option that of an unknown. If an unknown occurs in a response there is a formula to correct the score (see Appendix D).

Dementia is exhibited by marked cognitive and behavioural changes in the individual. The PAS cognitive decline and behavioural changes subset, has cut off points for the diagnosis of dementia. The cut off point for cognitive decline is $\geq 4.5$ (Jorm et al 1995), and for behavioural changes the cut off point is $\geq 1.0$. If scores are above these cut off points (the threshold) then it is very likely that dementia is present.

Table 5.4
PERCENTAGE OF PATIENTS WHO SCORED ABOVE THRESHOLD ON THE PAS SUBSETS OF COGNITIVE IMPAIRMENT AND BEHAVIOURAL CHANGE (n=30)

<table>
<thead>
<tr>
<th>Threshold</th>
<th>PAS (C) (% (n))</th>
<th>PAS (B) (% (n))</th>
</tr>
</thead>
<tbody>
<tr>
<td>% Above or equal to</td>
<td>*4.0</td>
<td>1.00</td>
</tr>
<tr>
<td>13.7 (n=4)</td>
<td>72.7 (n=16)</td>
<td></td>
</tr>
<tr>
<td>% Below</td>
<td>86.2 (n=25)</td>
<td>27.3 (n=6)</td>
</tr>
</tbody>
</table>

Note:
1. (C) Refers to cognitive impairment subset.
2. (B) Refers to behavioural change subset. There were 22 partners who completed this assessment on the patient.
3. * Denotes a set threshold .5 below that set by Jorm et al 1995 (see discussion following table).
The cognitive set gave a mean score of 1.7 (S.D. 2.29). This score is well below the point (≥ 4.5) where 80% of people with dementia are diagnosed with memory and concentration problems. Table 5.4 above gives the percentage of patient subjects who scored above and below the threshold of 4 (the recommended threshold is 4.5, but as there were no decimals obtained in the study group, in the score a lower threshold of 4 was set as it was a small sample). As 86.2% of patients scored below 4, this result suggests that patients have few problems with concentration and memory as assessed by the PAS.

The behavioural change subset gave a mean score of 2.73 (S.D. 2.99). This score sits on the 90th percentile for diagnosis of significant behavioural change. Diagnosed dementia cases have a score of ≥ 1.0. Table 5.4 above also shows that there were 72.7% of patients who scored above 1 in the behavioural change set. This result suggests that the patient with ESRD undergo a significant change in their behavioural pattern with dialysis.

**Table 5.5**
PERCENTAGE OF PATIENTS WHO SCORED 1 FOR EACH ITEM IN THE PAS COGNITIVE DECLINE AND BEHAVIOURAL CHANGE SUBSET (n=30)

<table>
<thead>
<tr>
<th>Item Number</th>
<th>*PAS (C)</th>
<th>*PAS (B)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>% (n)</td>
<td>% (n)</td>
</tr>
<tr>
<td>1</td>
<td>6.9 (2)</td>
<td>27.3 (6)</td>
</tr>
<tr>
<td>2</td>
<td>41.4 (12)</td>
<td>31.8 (7)</td>
</tr>
<tr>
<td>3</td>
<td>17.24 (5)</td>
<td>27.3 (6)</td>
</tr>
<tr>
<td>4</td>
<td>24.1 (7)</td>
<td>4.5 (1)</td>
</tr>
<tr>
<td>5</td>
<td>27.6 (8)</td>
<td>22.7 (5)</td>
</tr>
<tr>
<td>6</td>
<td>0 (0)</td>
<td>40.9 (9)</td>
</tr>
<tr>
<td>7</td>
<td>10.3 (3)</td>
<td>4.5 (1)</td>
</tr>
<tr>
<td>8</td>
<td>20.7 (6)</td>
<td>18.2 (4)</td>
</tr>
<tr>
<td>9</td>
<td>17.24 (5)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>10</td>
<td>N/A</td>
<td>22.7 (5)</td>
</tr>
<tr>
<td>11</td>
<td>N/A</td>
<td>27.3 (6)</td>
</tr>
<tr>
<td>12</td>
<td>N/A</td>
<td>31.8 (7)</td>
</tr>
<tr>
<td>13</td>
<td>N/A</td>
<td>0 (0)</td>
</tr>
<tr>
<td>14</td>
<td>N/A</td>
<td>22.7 (5)</td>
</tr>
<tr>
<td>15</td>
<td>N/A</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

**Note:**
There are 30 patients represented in the above table, following this assessment and the CFST one patient was excluded from the study.
Table 5.5 summarises the percentage of subjects who scored one for each item on the PAS (C) and (B) subsets. The behavioural change subset was a report by the partner of the patient, it was not a self-report from the patient themselves. The items in the behavioural change subset which ≥ 25% of partners assessed the patient at a score of 1 were: item 1 (patient lacks initiative); item 2 (patient is demanding and attention seeking); item 3 (patient is overly emotional); item 6 (patient is irritable); item 11 (patient is cantankerous); and item 12 (patient is sad in mood or depressed). 40.9% of partners felt that the patient was irritable.

The Color Form Sorting Test

The Color Form Sorting Test (CFST) has two possible outcomes; pass or fail there is no numerical score. Twenty-nine of the thirty patient subjects passed the CFST without difficulty. One subject failed as a result of residual disability from a previous cerebrovascular accident approximately twelve months prior to the study survey. This subject initially sorted into colours, but was unable to sort from colour into form. This was so even after demonstrating to the subject what was expected. This subject was excluded from the study.

All subjects in the partner group (n=22) passed the CFST without difficulty.

Severity of ESRD

The mean score for the total ESRD-SI was 25.03 (SD 15.9). This is a much higher mean score than that reported by Craven et al (1991) of 10.2 (SD 9.59). This higher mean score suggests this was a more chronically unwell group. There are ten disease categories assessed in the ESRD-SI. Table 5.6 presents the means and standard deviations for each category.
Table 5.6
THE END STAGE RENAL DISEASE SEVERITY INDEX MEAN SCORES
(Patient group n=29)

<table>
<thead>
<tr>
<th>ESRD - SI Total</th>
<th>Mean Score</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>ESRD - SI Disease Categories</td>
<td>Cardiac Disease</td>
<td>5.93</td>
</tr>
<tr>
<td>Cerebro-vascular Disease</td>
<td>3.63</td>
<td>3.83</td>
</tr>
<tr>
<td>Peripheral Vascular Disease</td>
<td>2.2</td>
<td>2.21</td>
</tr>
<tr>
<td>Bone Disease</td>
<td>2.07</td>
<td>1.92</td>
</tr>
<tr>
<td>Respiratory Disease</td>
<td>1.43</td>
<td>2.44</td>
</tr>
<tr>
<td>Visual Impairment</td>
<td>1.6</td>
<td>1.97</td>
</tr>
<tr>
<td>Autonomic Neuropathy and GIT Disease</td>
<td>2.1</td>
<td>2.05</td>
</tr>
<tr>
<td>Access and Dialysis Events</td>
<td>2.46</td>
<td>3.08</td>
</tr>
<tr>
<td>Diabetes Mellitus</td>
<td>1.40</td>
<td>2.94</td>
</tr>
<tr>
<td>Other</td>
<td>0.20</td>
<td>0.81</td>
</tr>
</tbody>
</table>

The mean score of the cardiac disease, bone disease, and the access and dialysis events categories are within the mild to moderate range. All the other categories are within the absent to mild range. Peripheral neuropathy, autonomic neuropathy and GIT disease are at the upper limit of the mild range.

The severity of renal disease in the patients was not unexpected when viewed in conjunction with age, primary renal disease, and co-morbid conditions. The major problem areas were cardiac and vascular related. Diabetes Mellitus accounted for 24.14% (n=7) of patients, which is consistent with Australian statistics as reported in Disney (1996).
Depression

The mean score on the full 21 item BDI for the patient group was 15.13, which is in the mild to moderate depression range. When the first 13 items are assessed, which is the CDI subset and excludes all somatic items, the mean score is 5.2. This indicates minimal depression. Beck and Steer state (1987) that a CDI score > 10 is moderate depression.

The mean score on the full 21 item BDI of the partner group was 7.75. This is in the nil to mild depression range. A CDI analysis was undertaken on this group, as many had an underlying chronic medical condition. The partner group had a CDI mean score of 2.5 markedly lower than the patient group.

Table 5.7 presents the percentage of patients and partners who attained BDI scores within the specified ranges as described by Beck et al (1988).

Table 5.7
LEVELS OF DEPRESSION IN PATIENT AND PARTNER GROUPS

<table>
<thead>
<tr>
<th>1. BDI Score Range</th>
<th>Patients (n=29)</th>
<th>Partners (n=22)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 10 nil - mild</td>
<td>46.66% (n=13)</td>
<td>72.73% (n=16)</td>
</tr>
<tr>
<td>10 - 18 mild - moderate</td>
<td>23.33% (n=7)</td>
<td>18.18% (n=4)</td>
</tr>
<tr>
<td>19 - 29 moderate to severe</td>
<td>26.66% (n=8)</td>
<td>9.09% (n=2)</td>
</tr>
<tr>
<td>30 - 63 severe</td>
<td>3.33% (n=1)</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. CDI Score</th>
<th>Patients (n=29)</th>
<th>Partners (n=22)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt; 10 moderate</td>
<td>16.67% (n=5)</td>
<td>4.5% (n=1)</td>
</tr>
</tbody>
</table>

The patient group had an incidence of 53.32% of depression in the mild to severe range, and 30% in the moderate to severe range. The partner group had an incidence of 27.27% of depression in the mild to severe range, and 9.09% in the moderate to severe range. This incidence is with the full 21 item BDI. The CDI suggests an
incidence of 16.67% of moderate depression. Figure 5.2 gives a more visual representation of the levels of depression found in the study group.

**Figure 5.2**
INCIDENCE OF DEPRESSION IN PATIENT AND PARTNER GROUPS (%)

![Bar Chart: Incidence of Depression](image)

Figure 5.3 illustrates the percentage of subject responses to each of the BDI items. This chart represents only those subjects who chose a greater than zero option for the particular item (Figure 5.3 presents individual items on BDI in descending order of importance to patients, items are not in the correct sequence as on the BDI). The major concerns of the patients are the decreased ability to work, fatigue, sleep disturbance, decreased interest in sex, and decreased life satisfaction. The partners major concerns were somewhat similar and included, fatigue (almost the same level as the patients), decreased interest in sex, decreased ability to work, and sleep disturbance.
Figure 5.3
PERCENTAGE OF SUBJECT RESPONSES TO INDIVIDUAL BDI ITEMS
(Patients n = 29 and Partners n = 22)
Extrapolations of the individual items, which make up the CDI (cognitive depression index), were then compared between patients and partners. Figure 5.4 below illustrates the findings.

**Figure 5.4**
SUBJECTS (PATIENTS AND PARTNERS) RESPONSES TO INDIVIDUAL ITEMS OF THE CDI (%)
Figure 5.4 shows that the major cognitive concerns are in relation to decreased life satisfaction ("I don’t enjoy things the way I used to; I don’t get real satisfaction out of anything anymore; I am dissatisfied or bored with everything"), an increase in irritability, and discouragement about the future for the patient group. For the partner group the major issues for concern were increase in irritability, discouragement about the future, life satisfaction, and self blame. Figure 5.4 suggests that the patients endorsed these items much more than the partners. The items dealing with life satisfaction, crying, self-disappointment, and suicidal thoughts were particularly different between the groups.

Figure 5.5
COMPARISON OF THE LEVEL OF DEPRESSION USING THE CDI SUBSET FOR PATIENTS AND PARTNERS (%)

Figure 5.5 above shows that there is approximately three times the number of patients who have moderate and above levels of depression that that of their partner when somatic items are excluded.
Figure 5.6 illustrates the level of depression in both the HD patient and partner group, as well as the CAPD patient and partner group. Overall the HD patients are marginally more depressed than the CAPD patients are. However, when the CDI is analysed (figure 5.7) depression levels with a score of greater than 10 (moderate depression) are similar in both patient groups. This suggests that HD patients have more somatic problems, however their cognitive results are similar. The HD group having 22.22% incidence and the CAPD group a 25% incidence. The HD partners are more depressed than the CAPD partners. This result may suggest that the higher level of assistance and responsibility required by the partner of a home haemodialysis patient might increase the risk of depression in this group.

Figure 5.6
COMPARISON OF DEPRESSION LEVELS OF HD AND CAPD PATIENTS AND PARTNERS USING THE FULL 21 ITEM BDI (%)

<table>
<thead>
<tr>
<th>Level of Depression</th>
<th>HD Patients</th>
<th>CAPD Patients</th>
<th>HD Partners</th>
<th>CAPD Partners</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nil-Mild</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild-Moderate</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate-Severe</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Severe</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The Psychological Effects of Dialysis on the Patient and their Partner

Chapter Five – Qualitative Results

Figure 5.7
COMPARISON OF HD AND CAPD PATIENTS AND PARTNERS LEVEL OF DEPRESSION USING THE CDI SUBSET (%)

Anxiety

The mean score of the patient group for the BAI was 10.03, which is in the mild to moderate range. The mean score of the partner for the BAI was 3.71, which is in the nil to mild range. Twelve subjects reported having no anxiety at all (n=6 patients, and n=6 partners). Table 5.8 gives the percentage of subjects who attained a BAI score within the ranges specified by Beck et al (1990).

Table 5.8
LEVELS OF ANXIETY IN PATIENT AND PARTNER GROUPS

<table>
<thead>
<tr>
<th>BAI Score Range</th>
<th>Patients (n=30)</th>
<th>Partners (n=22)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 10</td>
<td>53.33% (n=16)</td>
<td>86.36% (n=19)</td>
</tr>
<tr>
<td>10 - 18</td>
<td>30% (n=10)</td>
<td>13.64% (n=3)</td>
</tr>
<tr>
<td>19 - 29</td>
<td>13.33% (n=4)</td>
<td>0</td>
</tr>
<tr>
<td>30 - 63</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Notes
1. 12 people had no anxiety at all (6 patients, and 6 partners)
Figure 5.8 shows the percentage of subjects from each study group (patients and partners) responding to each BAI item with a score of ≥ 1. Over 50% of patients responded to items of indigestion and abdominal discomfort, unsteadiness, and inability to relax. The major response items for the partner group were indigestion and abdominal discomfort, flushed face, and inability to relax.

Figure 5.8
PATIENT AND PARTNER GROUP RESPONSES TO INDIVIDUAL BAI ITEMS (%)
The BAI can be divided into four subscales: neurophysiological, subjective, panic, and autonomic.

Figure 5.9 illustrates the percentage of patients and partners responding to each item within the neurophysiological subscale. A larger proportion of patients responded to these items than partners. Over 30% of patients responded to all items except that of feeling faint.

Figure 5.9
PERCENTAGE OF SUBJECTS RESPONDING TO BAI NEUROPHYSIOLOGICAL SUBSCALE

Figure 5.10 illustrates the percentage of subjects responding to items within the subjective subscale. Again the patient group had scores on all items higher than the partner group. Over 50% of subjects felt they were unable to relax, and 45% felt they were nervous.
Figure 5.10
PERCENTAGE OF SUBJECTS RESPONDING TO BAI SUBJECTIVE SUBSCALE

Figure 5.11 illustrates the percentage of subject responses to items in BAI panic subscale. As in the previous two subscales, the patients have a higher response rate to individual items than the partner group. Over 35% of patients felt they had a pounding/racing heart and feelings of choking. Interestingly both the patient and the partner had similar response rates to the fear of dying item.

Figure 5.11
PERCENTAGE OF SUBJECTS RESPONDING TO THE BAI PANIC SUBSCALE
Figure 5.12 illustrates the percentage of subject responses to BAI autonomic subscale. Over 50% of patients felt that they had indigestion and/or abdominal discomfort, as well as 40% of partners. Again the patients scored higher in all items then the partner group except for ‘flushed face’, which was higher in the partner group. This result may suggest that some partners are menopausal.

Table 5.9 gives the mean scores and standard deviations for each of the BAI subscales. These can be compared to the means reported by Beck (1990) which are in the second column of the table. Patients and partners anxiety is well below that of a generalised anxiety disorder.

Figure 5.12
PERCENTAGE OF SUBJECT RESPONSES TO BAI AUTONOMIC SUBSCALE
Table 5.9
COMPARISON OF STUDY GROUPS MEAN SCORES AND STANDARD DEVIATIONS WITH THOSE REPORTED BY BECK (1990) FOR A GENERALISED ANXIETY DISORDER

<table>
<thead>
<tr>
<th>BAI Subscale Total Sample</th>
<th>Mean Scores of BAI Subscales for Generalised Anxiety Disorder</th>
<th>Patients (n = 29)</th>
<th>Partners (n = 22)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neurophysiological</td>
<td>4.60 (SD 3.69)</td>
<td>3.97 (SD 3.61)</td>
<td>.68 (SD 1.21)</td>
</tr>
<tr>
<td>Subjective</td>
<td>8.63 (SD 4.14)</td>
<td>3.14 (SD 3.55)</td>
<td>1.14 (SD 1.83)</td>
</tr>
<tr>
<td>Panic</td>
<td>2.51 (SD 2.13)</td>
<td>1.66 (SD 1.74)</td>
<td>.55 (SD .91)</td>
</tr>
<tr>
<td>Autonomic</td>
<td>3.09 (SD 2.16)</td>
<td>1.72 (1.58)</td>
<td>1.18 (SD 1.76)</td>
</tr>
<tr>
<td>Haemodialysis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neurophysiological</td>
<td>3.44 (3.64)</td>
<td>1.0 (SD 1.41)</td>
<td></td>
</tr>
<tr>
<td>Subjective</td>
<td>3.00 (SD 3.32)</td>
<td>1.75 (SD 2.49)</td>
<td></td>
</tr>
<tr>
<td>Panic</td>
<td>1.78 (SD 1.56)</td>
<td>.5 (SD .76)</td>
<td></td>
</tr>
<tr>
<td>Autonomic</td>
<td>1.56 (SD 1.42)</td>
<td>2.13 (SD 2.53)</td>
<td></td>
</tr>
<tr>
<td>CAPD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neurophysiological</td>
<td>4.2 (SD 3.66)</td>
<td>.5 (SD 1.09)</td>
<td></td>
</tr>
<tr>
<td>Subjective</td>
<td>3.2 (SD 3.74)</td>
<td>.79 (SD 1.31)</td>
<td></td>
</tr>
<tr>
<td>Panic</td>
<td>1.6 (SD 1.84)</td>
<td>.57 (SD 1.02)</td>
<td></td>
</tr>
<tr>
<td>Autonomic</td>
<td>1.8 (SD 1.67)</td>
<td>.64 (SD .84)</td>
<td></td>
</tr>
</tbody>
</table>
The Patient and Partner Dyadic Relationship

The relationship between the patient and the partner was assessed by the use of the DAS as suggested by Sharpley and Cross (1982). Items 8, 10, 11, 25, 27, 28, and 31 only were used from the original 32 item DAS. These items were numbered 1 - 7 on the present study’s survey form (see Appendix H).

For items 1-6 the mean score for the patient group was 3.51 (S.D. .99), and for the partner group 3.55 (S.D. 1.38). These scores are slightly higher than that found by Sharpley and Cross (1982) of 3.29. This suggests that this study group viewed their relationship in a more positive light than the sample used by Sharpley and Cross. When items 1-6 were correlated with item 7 (degree of happiness in the relationship), r = .52, p < 0.01 and r = .51, p < 0.01 respectively) for the patient and partner. There was no significant correlation between items 1-6 and items 8 and 9, which suggests that the level of criticism had little effect on the patient/partner dyadic relationship.

Table 5.10 gives mean scores and standard deviations for the three subscales of the DAS. These subscales are dyadic cohesion, dyadic consensus, and dyadic satisfaction.

Figure 5.13 suggests that the patients and partners are generally in agreement for the dyadic consensus items (S.D. 1.18) in the partner group.

Figure 5.14 suggests that patients and partners are generally in agreement for the dyadic cohesion items. The partner group believed that there was an exchange of stimulating ideas more often than the patients.
Table 5.10
DAS SUBSCALE MEAN SCORES AND STANDARD DEVIATIONS FOR BOTH PATIENT (n=29) AND PARTNER (n=22) GROUPS.

<table>
<thead>
<tr>
<th>DAS Item</th>
<th>Patients</th>
<th>Partners</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>X (SD)</td>
<td>X (SD)</td>
</tr>
<tr>
<td>Dyadic Cohesion:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Calmly discuss something</td>
<td>3.58</td>
<td>3.77</td>
</tr>
<tr>
<td></td>
<td>(1.24)</td>
<td>(1.23)</td>
</tr>
<tr>
<td>Work together on a project</td>
<td>3.27</td>
<td>3.73</td>
</tr>
<tr>
<td></td>
<td>(1.76)</td>
<td>(1.20)</td>
</tr>
<tr>
<td>Have a stimulating exchange of ideas</td>
<td>3.04</td>
<td>2.86</td>
</tr>
<tr>
<td></td>
<td>(1.56)</td>
<td>(1.83)</td>
</tr>
<tr>
<td>Dyadic Consensus</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Amount of time spent together</td>
<td>3.35</td>
<td>3.14</td>
</tr>
<tr>
<td></td>
<td>(1.16)</td>
<td>(1.39)</td>
</tr>
<tr>
<td>Aims, Goals, and things believed important</td>
<td>3.85</td>
<td>3.82</td>
</tr>
<tr>
<td></td>
<td>(1.05)</td>
<td>(1.22)</td>
</tr>
<tr>
<td>Philosophy of life</td>
<td>3.96</td>
<td>3.95</td>
</tr>
<tr>
<td></td>
<td>(0.92)</td>
<td>(1.09)</td>
</tr>
<tr>
<td>Dyadic Satisfaction</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Degree of happiness of relationship</td>
<td>3.65</td>
<td>3.45</td>
</tr>
<tr>
<td></td>
<td>(1.06)</td>
<td>(1.18)</td>
</tr>
</tbody>
</table>

Figure 5.13
PERCENTAGE OF SUBJECTS RESPONDING TO DYADIC CONSENSUS ITEMS (PATIENTS n=26, PARTNERS n=22) ABOVE THE MEAN SCORE OF THE TOTAL SAMPLE
Figure 5.14
PERCENTAGE OF SUBJECTS RESPONDING TO DYADIC COHESION ITEMS (PATIENTS n=26, PARTNERS n=22) ABOVE THE MEAN SCORE

![Graph showing percentage of subjects above mean scores for dyadic cohesion items.]

Figure 5.15 suggests that the patients are happier in their relationship than the partner group.

Figure 5.15
PERCENTAGE OF SUBJECTS WHO VIEW THEIR DYADIC SATISFACTION ABOVE THE MEAN SCORE OF THE TOTAL SAMPLE FOR ITEM 7 ONLY

![Graph showing percentage of subjects above mean score for degree of happiness of relationship.]

Item 7, the global satisfaction item, had a mean score of 3.63 (SD1.04) in the patient group and 3.45 (SD1.18) in the partner group. These scores suggest that the patients and their partners were happy to very happy about their relationship, but the patients...
were more happy. Items 1-6 on the DAS had a significant positive correlation with item 7 ($r = .52, p < 0.00; r = .51, p < 0.00$) in the patient and partner group respectively. Which suggests the two agree with each other as expected. Item 7 is a global item which measures the degree of happiness in the relationship (Sharpley and Cross 1982).

Two other items (8-9) were included to assess the level of criticism each member of the dyad had of each other. Figure 5.16 illustrates that most patients feel that their partner is more critical of them than what they are of their partner. Partners feel that they are more critical of the patient than the patient is of them. That is, the partner was more critical and the patient agreed they were more critical. It is interesting to speculate if this accounts in someway for the higher depression in the patient group.

Figure 5.16
PERCENTAGE OF SUBJECTS RESPONDING TO ITEMS 8 AND 9 ABOVE THEIR MEAN SCORE

![Bar chart showing percentage of subjects responding to items 8 and 9 above their mean score.](image)
The mean score for item 8 was 6.2 (S.D. 3.19), which suggests that the patient group felt their partner was more critical than average. The mean score for item 9 was 4.5 (S.D. 2.94), which suggests that the patient group felt they were less critical of their partner than average. Items 8 and 9 in the patient group were not significantly correlated to items 1-6 (r=0.04 and 0.25 respectively).

In the partner group, the mean scores for items 8 and 9 were 4.22(SD 2.37) and 3.6(DS 1.62) respectively. These scores suggest that the partners felt that the patient was less critical of them than average, and they felt they were less critical than average of the patient.

Perception of Illness

Please refer to table 5.11 for the mean scores and standard deviations for the MOS SF-36 for both the patient and partner group. These mean scores represent the total overall score of the MOS SF-36, and those of each category within the MOS SF-36.

<table>
<thead>
<tr>
<th>MOS SF-36 Individual Categories</th>
<th>Patients</th>
<th>Partners</th>
<th>*Serious Condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total MOS SF-36</td>
<td>43.77 (SD18.18)</td>
<td>75.14 (SD16.01)</td>
<td>72.03 (SD4.04)</td>
</tr>
<tr>
<td>Physical functioning (PF)</td>
<td>31.17 (SD 25.04)</td>
<td>70.45 (SD25.92)</td>
<td>67.57 (SD7.04)</td>
</tr>
<tr>
<td>Role-Physical (RP)</td>
<td>23.33 (SD 35.92)</td>
<td>68.18 (SD38.72)</td>
<td>77.48 (SD6.20)</td>
</tr>
<tr>
<td>Bodily Pain (BP)</td>
<td>53.27 (SD 30.04)</td>
<td>67.95 (SD29.4)</td>
<td>75.76 (SD5.04)</td>
</tr>
<tr>
<td>General Health (GH)</td>
<td>29.87 (SD 21.44)</td>
<td>70.41 (SD 19.32)</td>
<td>69.84 (SD3.25)</td>
</tr>
<tr>
<td>Vitality (VT)</td>
<td>36.5 (SD 23.64)</td>
<td>61.36 (SD23.66)</td>
<td>75.00 (SD4.84)</td>
</tr>
<tr>
<td>Social Functioning (SF)</td>
<td>57.92 (SD 30.88)</td>
<td>79.55 (SD26.32)</td>
<td>69.84 (SD3.25)</td>
</tr>
<tr>
<td>Role-Emotional (RE)</td>
<td>66.67 (SD 42.88)</td>
<td>75.76 (SD 40.08)</td>
<td>53.78 (SD3.72)</td>
</tr>
<tr>
<td>Mental Health (MH)</td>
<td>62.93 (SD 23.56)</td>
<td>78.91 (SD15.91)</td>
<td>58.24 (SD4.80)</td>
</tr>
</tbody>
</table>

Note:
* Represents statistics reported by McCallum (1995) for patients with a serious condition.
Table 5.11 shows that the scores for the patient group are well below those of the partner group in all categories. Especially the categories of physical functioning, role-physical, general health, and vitality.

Table 5.12 presents results for all categories of the MOS SF-36, and for USA general population (two age groups).

<table>
<thead>
<tr>
<th>MOS SF-36 Individual Categories</th>
<th>USA General Population x (S.D.)</th>
<th>USA 55-64 year Age Group x(S.D.)</th>
<th>Patients x(S.D.)</th>
<th>USA 65-74 Age Group X(S.D.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical functioning</td>
<td>85.15 (23.28)</td>
<td>76.24 (26.32)</td>
<td>31.17 (25.04)</td>
<td>69.38 (26.26)</td>
</tr>
<tr>
<td>Role-Physical</td>
<td>80.96 (35.00)</td>
<td>73.66 (38.39)</td>
<td>23.33 (35.92)</td>
<td>65.54 (41.30)</td>
</tr>
<tr>
<td>Bodily Pain</td>
<td>75.15 (23.69)</td>
<td>67.51 (25.63)</td>
<td>53.27 (30.04)</td>
<td>68.49 (26.42)</td>
</tr>
<tr>
<td>General Health</td>
<td>75.95 (20.34)</td>
<td>65.62 (23.37)</td>
<td>29.87 (21.44)</td>
<td>62.56 (22.42)</td>
</tr>
<tr>
<td>Vitality</td>
<td>60.86 (20.96)</td>
<td>60.37 (22.59)</td>
<td>36.5 (23.64)</td>
<td>59.94 (22.12)</td>
</tr>
<tr>
<td>Social Functioning</td>
<td>83.28 (22.69)</td>
<td>81.37 (25.81)</td>
<td>57.92 (30.88)</td>
<td>80.61 (25.63)</td>
</tr>
<tr>
<td>Role-Emotional</td>
<td>81.26 (33.04)</td>
<td>80.26 (35.29)</td>
<td>66.67 (42.88)</td>
<td>81.44 (35.56)</td>
</tr>
<tr>
<td>Mental Health</td>
<td>75.74 (18.05)</td>
<td>75.01 (19.30)</td>
<td>62.93 (23.56)</td>
<td>76.87 (18.08)</td>
</tr>
</tbody>
</table>

The mean scores of the patient group are well below those of the USA general population, and that of two selected age groups. The age group 55-64 years includes the mean age (62.07 years) for the patient group, and the age group 65-74 years includes the mean age (67.36) of those patients > 60 years of age. The mean scores are also lower than the USA 75 years plus age group.
Table 5.13 summarises the mean scores and standard deviations for the partner group and same comparative groupings as for the patient group in table 5.9.

Table 5.13
COMPARISON OF MEAN SCORES OF INDIVIDUAL MOS SF-36 CATEGORIES FOR PARTNER GROUP (n=22), THE USA GENERAL POPULATION, AND THE USA 55-64 AND 65-74 YEAR AGE GROUPS (Males and Females)

<table>
<thead>
<tr>
<th>MOS SF-36 Individual Categories</th>
<th>USA General Population x(S.D.)</th>
<th>USA 55-64 year Age Group x(S.D.)</th>
<th>Partners x(S.D.)</th>
<th>USA 65-74 Age Group x(S.D.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical functioning</td>
<td>85.15 (23.28)</td>
<td>76.24 (26.32)</td>
<td>70.45 (25.92)</td>
<td>69.38 (26.26)</td>
</tr>
<tr>
<td>Role-Physical</td>
<td>89.96 (35.00)</td>
<td>73.66 (38.39)</td>
<td>68.18 (38.72)</td>
<td>65.54 (41.30)</td>
</tr>
<tr>
<td>Bodily Pain</td>
<td>75.15 (23.69)</td>
<td>67.51 (25.63)</td>
<td>67.95 (29.4)</td>
<td>68.49 (26.42)</td>
</tr>
<tr>
<td>General Health</td>
<td>75.95 (20.34)</td>
<td>65.62 (23.37)</td>
<td>70.41 (19.32)</td>
<td>62.56 (22.42)</td>
</tr>
<tr>
<td>Vitality</td>
<td>60.86 (20.96)</td>
<td>60.37 (22.59)</td>
<td>61.36 (23.66)</td>
<td>59.94 (22.12)</td>
</tr>
<tr>
<td>Social Functioning</td>
<td>83.28 (22.69)</td>
<td>81.37 (25.81)</td>
<td>79.55 (26.32)</td>
<td>80.61 (25.63)</td>
</tr>
<tr>
<td>Role-Emotional</td>
<td>81.26 (33.04)</td>
<td>80.26 (35.29)</td>
<td>75.76 (40.08)</td>
<td>81.44 (35.56)</td>
</tr>
<tr>
<td>Mental Health</td>
<td>75.74 (18.05)</td>
<td>75.01 (19.30)</td>
<td>78.91 (15.91)</td>
<td>76.87 (18.08)</td>
</tr>
</tbody>
</table>

The partner group mean scores are comparable with those of the USA 65-74 year age group. This is supported by the mean age (67.93) of those partners who were aged > 60 years. The mean score for the role-emotional was lower in the partner group than in the USA population of the same age. The mean scores of the partners are much better than the patients.

Figure 5.17, illustrates that the mean scores of the patient group are markedly lower than either the clinical depressed group or that of the congestive cardiac failure group in the physical functioning and general health areas (PF, RP, BP, GH, and VT). The mean scores of the patient group for the social functioning (SF) category are similar to the depressed group and lower than the CCF group. The mean scores for the role-emotional category are above both the depressed and the CCF group. The mean scores
for the mental health category are higher than the depressed group but lower than for the CCF group.

**Figure 5.17**
COMPARISON OF MOS SF 36 MEAN SCORES OF THE PATIENT GROUP (n=29) AND THOSE OF CLINICAL DEPRESSION AND CONGESTIVE CARDIAC FAILURE IN THE USA.

![Comparison of MOS SF 36 mean scores](image)

**Note:**
X axis represents the MOS SF 36 categories: Physical functioning (PF); Role physical (RP); Bodily pain (BP); General health (GH); Vitality (VT); Social functioning (SF); Role emotional (RE); and Mental health (MH).

Figure 5.18 shows that the HD patients have a lower score in the physical functioning (PF) and role-physical (RP) categories when compared to CAPD patients. CAPD patients scored lower than HD patients on mental health (MH) and social functioning (SF). Both groups were similar for general health (GH) and vitality (VT). This finding supports those from the BDI, which suggests that HD patients have more somatic type problems.
Figure 5.18
COMPARISON OF THE MEAN SCORES OBTAINED BY THE PATIENTS AND PARTNERS ON THE MOS SF-36
PATIENTS ON DIALYSIS FOR LESS THAN TWELVE MONTHS

On further investigation those patients who had been on dialysis for more than three months and no more than twelve months (range 5-10 months) were extrapolated from the total patient group. This subgroup consisted of 13.79% (n=4) of the total patient group. The partners of this small patient subgroup were also investigated and compared to the partner group as a whole. This partner subgroup consisted of 13.64% (n=3) of the total partner group. Again the BDI and BAI scores were below those of the total group, albeit marginal.

Figure 5.19 illustrates the patients and partners mean scores on depression and anxiety. These results were then charted against the mean scores obtained by the total study sample.

Figure 5.19
COMPARISON OF PATIENTS AND PARTNERS ON DIALYSIS FOR > THREE MONTHS BUT ≤ TWELVE MONTHS AND THE TOTAL STUDY SAMPLE
Results from this small sub-group suggest that the incidence of depression and anxiety may increase with increasing time on dialysis. However, this was not supported by any significant correlation between depression and anxiety and time on dialysis.

Results also suggest that the individual’s perception of their health decreases with increasing time on dialysis (Figure 5.20). This is an expected result as the longer a person is on dialysis the higher the incidence of consequential complications associated with time on dialysis (such as bone disease, cardiac disease, neuropathies). Therefore, the longer on dialysis the worse the patients perceive their own health. This may be related to the physical decline, reported by subjects, in association with being on dialysis. This physical decline may increase the incidence of depression in the ESRD population as was demonstrated by the results of the full 21 item BDI. This showed that the somatic items were major issues of concern for those on dialysis.

**Figure 5.20**
COMPARISON OF MEAN SCORES OF PATIENTS AND PARTNERS WITH DIALYSIS FOR LESS THAN TWELVE MONTHS WITH THE TOTAL PATIENT AND PARTNER GROUPS

![Comparison of mean scores](image)

**Note:** Physical functioning (PF), Role-physical (RP), Bodily pain (BP), General health (GH), Vitality (VT), Social functioning (SF), Role-emotional (RE), and Mental health (MH).
Results from the small sub-group also suggest that the partners perceive their health as below that of the whole group in the following MOS SF-36 categories: i) physical function; ii) physical role; iii) general health; iv) vitality; and v) social functioning. These results suggest that as the time on dialysis increases the partner’s perception of their own health improves somewhat in these categories. This may be evidence of an adaptation effect. Whereas the emotional and mental health categories decrease with time on dialysis which may be a result of the impact of long term dialysis on their psychological functioning.

When the two small subgroups were compared with each other, results suggest that the levels of depression and anxiety were very similar (the full 21 item BDI were compared). Results further suggest that both the patient and the partner view their individual health as being similar in the physical functioning, physical role, bodily pain, general health, and vitality categories of the MOS SF-36. However, the partners view their social functioning as markedly lower than that of the patient. This result may suggest that the impact of home dialysis (all subgroup subjects were on home dialysis), which affects the partner’s social activities. This view is supported by clinical experience, which has observed how the partner’s provide assistance and support for the patient during the time on dialysis. This support is not just during the dialysis procedure time, but is also on going into all daily activities.

DEATHS

During the period of this study, there were patients who died. Two deaths were as a result of cardiac events, one from scepticaemia, and one from an unknown cause.
Figure 5.21 below shows each subject (1-4) who died and their individual scores on the BDI, CDI, and DAS.

Figura 5.21
INDIVIDUAL SCORES OF PATIENTS WHO DIED (n=4) FOR THE BDI, CDI, BAI AND DAS

All subjects scored on or above the mean scores for the BDI, CDI, and BAI. This suggests that higher depression and anxiety levels may be associated with a decreased survival rate. Although the results may further suggest that depression and anxiety increase with a decrease in health status. The numbers are too small to really support these statements. Subjects 1, 2, and 3 also have DAS scores on or above the mean, which suggests that they have a positive marital relationship with their partner.

Figure 5.22 shows that the patients who died had markedly lower scores on the MOS SF36 in comparison to the total study patient group. This result may support the MOS SF36 as being a valid assessment of the dialysis patient’s perception of their own health and their mortality risk.
Figure 5.22
INDIVIDUAL SCORES FOR ALL MOS SF-36 CATEGORIES FOR EACH SUBJECT WHO DIED DURING THE STUDY AND THE TOTAL SAMPLE MEAN SCORES.
Subjects were asked to respond to two questions. These were audiotaped, then transcribed verbatim, and then analysed for common themes. The two questions employed the psychotherapy technique of free association. Once the questions were asked the subjects were asked to speak for five minutes without interruption. The complete questions can be referred to in Appendix C.

QUESTION ONE

“I would like you to speak for five minutes telling me what kind of a person (partner’s name) is and how you get along together.”

PATIENT GROUP RESPONSES

Analysis of the patient group responses to question one identified the following themes:

A Good Relationship with their partner
This category included statements by the patient, which were positive about their relationship with their partner. Overall there were no negative comments made about their partners. The patients felt that their relationship with their partner was very positive.

Some of the statements made by the patients were:
‘...we’ve only been married for 38 years...’ (11, L19)

‘...I think I’d put up with him for another 40 years...’ (21, L 15-16)

‘...we get on pretty well...we have no fights...only verbal ones...’ (22, L5-6)

‘...I wouldn’t trade her for anyone else...’ (22, L8)

‘...he’s been right behind me all the way...’ (28, L53)

‘...she’s a good wife,...cook and mother...’ (15, L2-3)

‘...he was just wonderful...I’m very, very happy to have him...’ (18, L38-40)

‘...my wife is ideally suited with me...’ (14, L2)

Personality Traits

The patients expressed that their partners had ‘a temper’, were ‘loving and caring’, overprotective, ‘kind and warm’, and at times ‘impatient’.

Concerns for Partners Health

Some patients expressed concern regarding their partner’s health. This may have been from a self-centered point of view as they realise they cannot dialyse without their partner especially within the home environment.

Some of the statements made by the patients were:

‘...I just hope she can kick on putting these needles in me...’ (22, L15-16)

Recognition of the extra workload on their Partner

A few patients expressed recognition of the extra workloads their partners were carrying because they were on dialysis.

Some of the statements made by the patients were:

‘...[husband] is very kind, and I couldn’t manage without him...’ (21, L1-2)
'*•  •  •  he helps me put the washing out...” (21, L4-5)

'*•••I just wish he could ... go out more... but the way things are we're just handicapped...' (21, L8-10)

'*•••I think I overwork him sometimes...’ (18, L31)

Partners Resentment

This category included statements by the patients, that in some way they felt that their partners resented them.

Some of the statements made by the patients were:

'*•••I feel sometimes that he gets a bit... fed up with the routine and the way things hold you back all the time... there’s no spontaneity...” (12, L77-79)

PARTNER GROUP RESPONSES

Analysis of the partner group responses to question one identified the following themes:

Personality Traits

This category involved those traits as expressed by the partner, which described the patient. The partners were better able to verbalise the patient's traits and identified more negative aspects than did the patient group.

Overall the identified traits were very positive. Patients were described as ‘marvellous’, ‘courageous’, ‘pleasant and friendly’, ‘loving and caring’, ‘independent’, ‘pretty strong’, ‘private and quiet’, ‘even tempered’, and ‘patient’.
Negative aspects included ‘selfishness’, ‘inward looking’, ‘does not want responsibility’, ‘becomes impatient’, ‘decline in quality of personal relationships as illness deteriorates’.

Some statements made by partners were:
“...he’s very caring and loving...” (11, L1)

Importance of Family

This category involved those statements made by the partner regarding the importance of family to the patient.

Overall the family was very important to all patients and were expressed as having a ‘good relationship with the children’, ‘he brought all his family together again’, ‘very family orientated’, ‘thankful that the children are healthy’. Many partners also expressed their and the patient’s pride in their children’s achievements.

Some statements made by partners were:
“...but we have lots of support from our children...” (2, L52-53)
“...the kids adore him...” (10, L4)
“...he’s a very family oriented person...” (10, L14-15)

Negative Emotions

This category involved those statements made by the partners that patients have expressed negative emotions.

The emotions identified included ‘doesn’t show a lot of emotion, except anger’, ‘he gets angry”, ‘he gets bloody cranky at times’, ‘he gets depressed at times’.
Some of the statements made by the partners were:

“...now and again he just feels like giving up, but he doesn’t...” (6, L8-9)
“...he gets very cranky at times...” (11, L4)
“...he gets depressed because he can’t do what he used to...” (11, L3-4)
“...it doesn’t take much to fly off the handle with the children...” (20, L43-44)
“...he’s certainly more inward looking...” (20, L48-49)
“...I can see that there’s been a decline in his relationships with people as he got more... ill...” (20, L58-59)
“...she just can’t express or show her feelings unless it’s anger...” (5, L22-23)

Many partners also stated how they become angry with the patients, but would then try and rationalise their feelings, “I get cranky with him...but I suppose I shouldn’t really’.

“...when he gets cranky I have a go back...I think at times I nag him, but I don’t mean to...” (11, L22-25)

The partners may also be responding to the depression in the patient by being more critical of them.

A Good Relationship with their Partner

This category involved statements by the partner, which had a positive connotation for the partner/patient relationship. Overall most relationships were very positive as they were with the patient group.

Some of the statements by the partners were:

“...in some ways this dialysis has brought us closer...” (22, L4-5)
“...we just fit hand in glove...” (14, L6)
“...we are...still enjoying our life together...” (2, L8)
"...I would say as marriages go, ours is as good as the next...and better than most..."

(2, L17-19)

"...we have our ups and downs...but we think the world of each other..." (6, L1-3)

"...we spend all out time together, and just about always have..." (21, L11-12)

"...we just seem to fit together..." (21, L17)

"...friends, lovers I suppose we still are..." (10, L2)

Loss

This category involved statements in which loss was described.

Some statements made by the partners were:

"...I can’t do exactly what I want to do anymore..." (14, L33)

"...we have a very good sex life, now we’re too tired half the time...I hope that comes back..." (14, L113-114)

"...I am really missing what [he] used to be like..." (20, L17-18)

"...we’ve always had a good sex life too...but that seems to have gone down the tube..." (20, L34-36)

6.2 QUESTION TWO

"I would like you to talk to me for a few minutes about your life at the moment the good things and the bad, what it is like for you."

PATIENT GROUP RESPONSES

The following themes were identified:
Uncertainty about Health Status

Some of the statements made by the patients were:
‘...so I come home [from hospital] and battle on until the next illness strikes me...’
(29, L39-40)
‘...the main thing is not feeling good. I never feel well, never, ever feel well...’ (18, L1-2))

Impact of Dialysis

Some of the statements made by the patients were:
‘...well being on dialysis is fairly lousy...’ (9, L1)
‘...I can’t sit and crochet...or knit or sew or do things I used to do because my arm, I’ve got to keep it still...’ (21, L25-27)
‘...I get sick and tired of this dialysis...’ (11, L28-29)
‘...it [dialysis] ties up so many hours...’ (22, L33)
‘...I’m glad this didn’t happen until after I was 70, I would have hated it at 36...’
(22, L22-23)
‘...I’d probably be dead by now if it hadn’t been for the dialysis...[its] keeping me alive...’ (20, L17-19)
‘...it [dialysis] does affect you in many ways...’ (19, 13-14)
‘...you’re forever thinking oh, I’ve got to do the next one...’ (12, L8-9)
‘...if I don’t do it [dialysis] I don’t live...’ (12, L12-13)
‘...its [dialysis] just a bummer...’ (28, L19)

Social Isolation

Some of the statements made by the patients were:
‘...but as soon as your sick ...no-one wants to come and see you...’ (6, L44-45)
‘...I haven’t been out of the house now for about seven months...’ (6, L81-82)
‘...I don’t go out very often because I have to be home to do the dialysis...’ (29, L5-7)

Denial of Medical Condition

Some of the statements made by the patients were:

‘...things haven’t changed much...’ (10, L1)

‘...I know I’ve got a couple of problems...’ (10, L1-2)

‘...I’ve got no problems...’ (11, L32-33)

‘...I keep everything in and I don’t tell anyone that I’m sick...’ (6, L33)

Patients who had major medical problems as well as ESRD made the first three statements above. These problems include terminal cardiomyopathy, a lower back problem (not as a result of peritoneal dialysis) which has major implications to physical mobility and pain experienced. The last statement was made by a patient who has serious conditions which have arose from Diabetes Mellitus such as severe peripheral vascular disease and neuropathy which prevent them from walking any more than a few meters, and unstable angina. These statements seemed very unrealistic given the medical conditions of these patients. These patients were aware of their poor medical condition and future outcome.

Lifestyle Changes

Some of the statements made by the patients were:

‘...I’m limited to do things...’ (30, L1)

‘...I am a little disappointed with my life at present...’ (4, L1)

‘...life for me now is not the same as it used to be...I am restricted a hell of a lot...’ (8, L1-3)

‘...we’ve both had an active part in the Bush Fire Brigade...with my health going down, I won’t be taking such an active part...’ (14, L13-15)
Suicide Ideation

Some of the statements made by the patients were:

‘...I sometimes wake up in the morning and wish I were dead...’ (6, L74-75)

‘...I wish I could just die and get it over with...’ (25, L7)

‘...sometimes I just feel like shooting myself...’ (6, L31)

Anger

Some of the statements made by the patients were:

‘...up until this [dialysis] I was fairly healthy...’ (4, L4-5)

‘...you do your best and as soon as your sick they just give you a kick...’ (6, L52-53)

‘...well I get bloody fed up...’ (6, L59)

Depression

Some of the statements made by the patients were:

‘...I do get down sometimes...’ (20, L20-21)

‘...the last few months have been good...but the three years previous...they were really bad...’ (5, L82-83)

‘...it seemed like I was always crying, never stopped...’ (5, L166-167)

‘...I'm down in the dumps sometimes...but I just have to put up with it...’ (8, L8-10)

‘...sometimes when I hear how long the others are waiting for kidneys [transplants] I get down in the dumps...I've been on the [waiting] list for two years now...some...have been on the list for five years...’ (5, L56-59)

‘...I get a bit depressed at times...’ (4, L5-6)

Fantasy Ideation

Some of the statements made by the patients were:

‘...I just wish I could get a kidney...” (12, L46-47)
The Psychological Effects of Dialysis on the Patient and their Partner

Chapter Six - Qualitative Results

'I want to feel normal...' (12, L52)

'I can't make it better, I can't get my kidneys back...' (28, L39-40)

'I feel I would just like to say, oh well I don't have to do it [dialysis] for two weeks, and really have a good holiday...' (12, L22-24)

'I think that when I get a kidney transplant...it's just going to be wonderful...' (12, L49-51)

PARTNER GROUP RESPONSES

The following themes were identified from question two:

Lifestyle Changes

This category described those changes which have occurred since the commencement of dialysis. This category includes role changes within the family. For example, a husband who was the primary wage earner commences dialysis and as a consequence loses his job. This change leads to the wife obtaining employment to support the family. Therefore financial difficulties have a major impact on lifestyle. As was seen in the quantitative results the majority of dialysis families are on social welfare payments. The impact of dialysis on their life is great in that the partner has less time for themselves, and most partners felt that holidays were no longer possible. Most partners felt that the organisation of a holiday was just too difficult, and they were also worried about the medical care which may/may not be available to them on a holiday.

Some of the statements made by the partners were:

"...the main thing is him not being able to do what he used to...he hates seeing me doing it all..." (11, L7-9)
“...our life is very different and restricted...” (2, L49)

“...if we could get away for a few days, in between injections and doctors and God knows what I think that would be a great help...” (10, L99-101)

“...I had presumed that when he went onto dialysis that he would get back to what he had been like before he became ill...” (20, L13-15)

“...money has been a problem...” (20, L19)

“...the stress of it [husband’s illness] has played a big part...the fact that I’m worse off now...” (20, L)

“...he just doesn’t want the responsibility [paying bills etc] I don’t think...” (20, L69-70)

Dialysis Commitment

Partners reported that the commitment to dialysis affects their lives. Many partners referred to dialysis as ‘it’ or ‘that’. They felt they were just as restricted as the patient by dialysis because of the patient’s need of them and also their own worries about the patient.

Some of the statements made by the partners were:

“...this...dialysis is forced on you...” (14, L82)

“...it [dialysis] does sort of ruin your life...” (11, L60)

“...it [dialysis] just stops your life a fair bit, its mucked up our life...” (14, L76-77)

“...we had a few bad frights...” (14, L86-87)

“...the only thing about him being on the bags you can’t go out anywhere...” (11, L38-39)

“...I just keep an eye on him...he does nod off to sleep sometimes...” (10, L)

“...he might whinge about doing them, but he does them...” (11, L51-52)
“...I won’t go out and leave him on his own...because he’s too sick to be left on his own...” (11, L70-71)

“...before my wife...went on dialysis I wasn’t aware of just how big a situation this really is...” (2, L47-48)

“...it [dialysis] affects me to the point of frustration...we know there is no light at the end of the tunnel...” (2, L83-87)

“...the only thing that worries me is when he’s sick and I can’t help him...” (6, L10-11)

“...we’re starting to come to terms with it [dialysis]...” (10, L1-2)

“...life is pretty dull...” (21, L)

“...it, the dialysis does take up a lot of time and...it’s four times a day...” (19, L9-10)

“...I feel as though I need to get away. He wants me to go away but I’m not game to leave him by himself...someone’s got to be here...” (10, L103-107)

**Importance of own Health**

Partners expressed that they worry about the state of their own health. They were concerned as to what would happen to the patient if they became ill. The partners acknowledged that the patients were concerned about their health and the impact dialysis was having on their lives.

Some of the statements made by the partners were:

“...I worry myself about my own health...I worry about my legs and my general health is starting to fail...” (2, L100-104)

“...as long as I stay healthy...otherwise heaven knows what would happen if I were sick...” (6, L30-32)
Emotional Responses

Partners expressed that they felt many emotions. They admired the patient’s courage and staying power. They also expressed gratitude that the patients were alive.

Partners also expressed a wish that the patients be well. Feelings of resentment, anger, depression, guilt, were all mentioned. Although after mentioning that they may have arguments with the patient, or get angry with them, the partners all attempted to rationalise these feelings thereby suppressing their own feelings. Most partners felt that there was no light at the end of the tunnel, as most patient subjects were not on the kidney transplant list and therefore would require dialysis for the rest of their lives.

Some of the statements made by the partners were:

“...it's [dialysis] nerve racking...” (14, L84)

“...I know [he] gets really upset because he’s so sick and I try and persevere and not get annoyed with him...” (6, L5-7)

Fatigue

Partners also expressed at great length their own fatigue which they say is as a result of the stress they have had as a result of the dialysis therapy. All but three patient subjects were dialysed within their own homes. Therefore the partners have a greater responsibility as they assist with the dialysis treatments for their partners.

Some of the statements made by the partners were:

“...I've always been a person who needed my eight hours [sleep] a night... of course now I'm not getting it three days a week... I'm up until after midnight...” (14, L35-37)

“...I... I just get very tired...” (14, L91)
"...I do get tired, because of the chores..." (2, L112)

"...I'm just exhausted and stressed out..." (20, L77)

Social Isolation

Social isolation was a major concern for the majority of partners. The partners felt they had become housebound as a result of dialysis, and that their life was as restricted as the patient's. Many partners stated that they would like to be able to go on a holiday.

Some of the statements made by the partners were:

"...we don't go out for months on end, and to sit with just the two of you...I do think at times you've just got to get out..." (11, L68-70)

"...I can't visit the family because of [his] illness...with them working and so far away they can't come and see us...thank goodness I'm a stay at home otherwise I'd probably get depressed because I can't do anything..." (6, L14-23)

"...I don't see many people nowadays...I don't have ...the contact with people that I used to have...I see more women than I do men now simply because of [dialysis]..." (21, L21-30)

Need for Family

All partners expressed that their families were important to them. Both in pleasure that they felt in their children's achievements, and for their support. Most partners stated that they had very supportive families, but then went on to say that these family members lived at a distance from them and had their own lives to live. Many partners stated that they had difficulties with this as where they used to visit the children prior to dialysis, now they had to rely on the children to visit them, and these visits may be infrequent.
Need for Acceptance of their Situation

Most partners expressed somewhere in their response that you had to accept it (dialysis) and get on with your life.

Some of the statements made by partners were:

“...I think we are learning to cope...” (10, L65)

“...as my wife says things could be worse...” (2, L54)

Resentment

Partners expressed that they resented the patient’s need of them, and the loss of the patient’s health. Many of subjects, who participated in this study, had worked and saved to enable them to retire to the small coastal villages. The partners expressed regret at the loss of their partner’s health, which has decreased their life satisfaction. Many of the couples had planned a healthy, happy, and active retirement.

Some of the statements made by the partners were:

“...I feel on occasions that there is a little self pity [in the patient]...” (2, L93-94)

“...sometimes you look around at other people the same age as yourself and you see that their activities are so fruitful...and you’re restricted...” (2, L94-97)

“...I suppose in a way I’ve resented him, he doesn’t take up a lot of time...its just we don’t seem to be able to have much of a social life...” (10, L13-14)

“...I wish I had somebody that I could sit back and say gee I’m not well today or I’m aching and they look after me instead of having to keep going with him...” (22, L35-37)
The Good Things

The partners expressed no good things in their life except for gratitude that the patients were able to live because of dialysis, and the fact that their children were healthy.

Some of the statements made by partners were:

"...he's alive and I suppose that is the main thing to me...that he's alive and still going..." (11, L65-66)

CONCLUSION

The major concerns of the patient group were i) the impact of dialysis on their lives and the restrictions that this imposed; ii) feelings of depression; iii) life-style restrictions; iv) uncertainty about their health status; and v) social isolation. Problems identified, which may impact on the health care providers, were i) the level of denial used by patients; ii) suicide ideation; iii) fantasy ideation and unreal expectations; and iv) repressed anger at their (patients) situation.

In comparison the major concerns for the partner group were i) the life-style changes and restrictions imposed by dialysis; ii) the commitment required by dialysis (it was very worrying to note that one partner felt that home dialysis had been forced upon them); iii) resentment and suppression of their own feelings for the perceived good of the patient; iv) social isolation; and v) they perceived that they had to accept it (dialysis). Partners also verbalised the need of family support. They all stated that family was important to them and also to the patient. Some partners gave clarifying statements after they stated that they had supportive families. These statements generally addressed issues that involved long distances that family members were
from them, and the fact that these family members also had families of their own to care for. When compared to the patient group, the social isolation as experienced by the partners was a more important issue. Both groups expressed fatigue as a major concern. Similarly partners had few expressions of anything good in their lives. Those partners, who expressed positive views, involved statements, which expressed gratitude that the patient was alive, and recognition that without dialysis they would die.

The overall impressions from the analysis of all transcribed responses suggest that: the patient group as a whole are angry and depressed mainly due to their need for dialysis and the progressive deterioration in physical activity tolerance that occurs as a result; and the partner group have undergone major lifestyle changes since the commencement of dialysis, and that they feel stressed as a result of the responsibility they have in relation to dialysis there being a feeling of no light at the end of the tunnel for them.
CHAPTER SEVEN

DISCUSSION AND CONCLUSIONS

This chapter discusses the results from the study into the psychological effects of dialysis on the patient and their partner. Addressing each of the study’s objectives sets out the chapter.

STUDY OBJECTIVE ONE

The first objective of this study was to identify the incidence of depression and/or anxiety in the dialysis patient and their partner and to investigate if there is any relationships between study groups or across treatment modalities.

DEPRESSION

Patients

The BDI (full 21 items) demonstrated that there was a significant level of depression found in the patient group of 53.33% in the mild to severe range, and 30% in the moderate to severe range. When the 8 somatic items were removed, leaving 13 items known as the CDI, the CDI demonstrated only a 16.67% incidence of moderate depression.

These results could suggest that dialysis patients might have a chronic dysphoric mood state more so than an actual clinical depression. Fishbein (1994) reported that ESRD patients might be reacting to severe stress associated with disability, role changes and financial losses. The results of the present study support this view. The
total BDI scores suggest that a large proportion of patients were depressed compared to the CDI subscale. This suggests that the physical limitations imposed by dialysis may be the basis of depression. Depression may be a marker for the severity of renal disease as suggested by Kimmel (1992). Support for this was evidenced in the results from the patient scores on the MOS SF-36. These suggest that physical limitations negatively affect the individual’s perception of their own health. Further support for this stand was evidenced by the comments from the patients’ transcribed responses, which stated that physical limitations were a major concern for them.

The effects of ESRD and dialysis itself impose these physical limitations. The physical limitations increase as the severity of disease increases, and therefore it was expected that the level of depression would also increase. However, there was no correlation between the ESRD-SI and the BDI or the CDI, yet there was a significant negative correlation between the MOS SF-36 and the BDI and the CDI. This supports the results presented by Sacks et al (1990), and Shulman et al (1989), in that depression and the individual perception of illness are strongly associated, independently of actual ESRD status. There was a significant correlation between all categories of the MOS SF-36 and the BDI and the CDI.

There was no significant correlation between depression scores and months on dialysis for the total sample. This suggests that time on dialysis does not influence depression. Those patients who had been on dialysis for less than twelve months were extrapolated and compared to those of the general sample. Results suggest that depression and anxiety may increase with an increasing time on dialysis. There were only 4 patients who had been on dialysis less than twelve months and so the results should be viewed cautiously. This result conflicts with those reported by Kutner et al (1985), which suggested that depression decreases as time on dialysis increases due
Biophysical responses as a consequence of the loss of homeostasis from ESRD may also play a role in the development of depression, as there is substantial hormonal dysfunction associated with uremia in ESRD. This may play a role in the development of depression, but this association has not been proved.

From the BDI the major issues of concern was the patients decreased ability to work, fatigue, decreased interest in sex, an increase in sleep disturbance, and decreased life satisfaction. If the CDI was viewed separately the areas of most concern to the patients were decrease a life satisfaction, an increase in irritability, and discouragement about the future. Studies by Devins et al (1990); Killingworth et al (1996); Lok (1996); Ferrans and Powers (1993); and Klang et al (1996) support this result.

The results from this study suggest that the patient’s physical decline as a result of dialysis has a major impact on how they perceive their health and their depression level. Studies by Devins et al (1990); Wichowski et al (1997); Ferrans and Powers (1993); Klang et al (1996); and Sacks et al (1994) support the association.

The patient study group was divided into two groups, those on HD (n=9), and those on CAPD (n=18). These groups were than compared on BDI and CDI scores. On the full 21 item BDI 50% of the CAPD group had an incidence of depression in the mild to moderate level, and the HD group had 55.5% incidence in the mild to severe range. This finding may suggest that there may be a slightly higher incidence of depression in the HD group. When the CDI scores of the two groups were compared, the HD group had a 22.22% (n=2) incidence of moderate depression, and in the
CAPD group 11.11% (n=2). This result also may suggest that there is an increased incidence of depression in the HD group, but the numbers are too small to be conclusive.

Partners

The partner group had a much lower mean score for the full 21 item BDI when compared to that of the patient group. However, when the partner group BDI mean score (7.75) was compared to the CDI mean score of the patient group, the partner group had greater depression levels. When the individual items of the BDI are compared, the major issues of concern for the partner group in order of importance was fatigue, decreased sexual activity, increase in sleep disturbance, and a decreased ability to work. All of these concerns are somatic in nature, and can be related to the impact of dialysis on the partner's life. Of the cognitive items the two most important issues of concern were that the partners felt more irritable, and were more discouraged about the future.

These results were supported by those of Lowry et al (1994) who said that the spouses also experience loss, role changes and financial difficulties, as does the patient. The Lowry et al study also suggested that the spouses felt deprived, hostile and were easy to anger. These factors were also highlighted in the present study in the transcription of the partner responses in the five-minute speech samples. It is possible that the partners were using denial also as a coping mechanism. Clinical experience would suggest that the partners have higher levels of depression than they admitted to in this study. Burton et al (1988) suggested that there was a direct link between the spouse's perception of social support and their psychological...
functioning. Again the transcriptions of the partners five-minute speech samples indicated that the social isolation which occurred as a consequence of dialysis was a major issue, but this was not reflected in the depression scores.

There was no significant relationship found between the levels of depression in the patient and partner groups. Those patients and partners involved with haemodialysis had a higher level of depression when compared to those on CAPD.

When haemodialysis patient's CDI scores and partners BDI scores were compared, approximately 60% of partners and approximately 20% of patients had a score of more than 10. This is in the moderate and above level. Whereas of those on CAPD, approximately 23% of patients and 5% of partners had a score of more than 10. This result suggests that haemodialysis is more likely to lead to a higher level of depression than CAPD. This could be related to the fact that haemodialysis is more stressful for the patient and partner because of the involvement of complex technologies.

ANXIETY

Patients

The mean scores for the BAI in the patient group demonstrated that there was an incidence of anxiety of 43.33% in the mild to severe range, with 53.33% having nil to mild anxiety levels. The areas of concern in the BAI were indigestion/discomfort in abdomen, unsteadiness, inability to relax, shakiness, and feelings of choking. When the four subscales of the BAI were calculated out the patients scored higher in all subscales when compared to their partners. All of the items in the neurophysiological, panic, and autonomic subscales are physiological responses, which may occur in
relation to dialysis itself. The subjective subscale is not based on physiological response but more on the patient's feelings. Unfortunately the BAI does not distinguish between anxiety felt generally or in relation to the dialysis procedure itself. There were six patient subjects who scored zero on the BAI; they did not report even the mildest anxiety levels for any of the items. This may also suggest that the patients may be using denial. Kutner et al (1985) reported an incidence of 48% of symptomatic anxiety in their sample, and that there was a strong correlation between anxiety and depression ($r = .69, p< 0.00$). The results from this study supports this finding by demonstrating a highly significant correlation between depression (BDI) and anxiety (BAI) of $r = .71$, $p < 0.00$. There was also a significant correlation with cognitive depression (CDI) and anxiety (BAI) of $r = .77$, $p < 0.00$ which is slightly higher than with the full BDI.

As with depression, the patient sample group was divided into those on HD, and those who were on CAPD. Both patient groups had an incidence of anxiety in the nil to mild range of 55.56% (HD n=5, CAPD n=10). HD patients had a slightly higher incidence (33.33% n=3), than the CAPD group (27.78% n=5), in the mild-moderate range. The CAPD group had a higher incidence (16.67% n=3), than the HD group (11.11% n=1) in the moderate to severe range. Neither group had any incidence in the severe range.

When the results of the BAI were analysed into the neurophysiological, subjective, panic, and autonomic subscales there was a higher percentage of patients responding to all items than the partner group.

Overall the results show that there is a significant level of anxiety in the patient group. But as with depression it is difficult to argue whether the anxiety is an actual
clinical anxious state or is a reaction to the dialysis procedure itself.

Partners

The partners overall had less anxiety than the patient group. The partner group evidenced an 86.36% incidence of anxiety in the nil to mild range, and only 13.64% in the mild to moderate range. Partners scored consistently below the patient group in all the subscales of the BAI. Similar trends were shown in both the patient and partner groups in the subjective subscale. Both the patients and partners fear of dying in the panic scale was very similar. Interestingly both the patient and the partner group rated indigestion and abdominal discomfort as the issue of most concern from the autonomic subscale.

The results from this study suggest that there is a significant level of depression and anxiety within the patient group and less so in the partner group. These results should be tempered with caution in respect to two factors. Firstly, it is difficult to separate actual clinical depression and anxiety from what may be a chronic reactive type dysphoric mood, as the diagnosis of depression and anxiety is reliant upon many somatic items which can be associated with ESRD itself. Secondly, it is possible that both patient and partner groups are using denial as a coping mechanism to deal with a chronic illness. Clinical experience and qualitative information from patients and their partners would suggest that the level of depression and anxiety within both the patient and partner groups would have been higher.

As with depression there was no significant relationship between the levels of anxiety demonstrated between the patient and partner groups. The results from this study do suggest that the levels of anxiety are similar in those patients on haemodialysis and
peritoneal dialysis, but there is more anxiety in the partners of those patients on haemodialysis compared to those on peritoneal dialysis. Clinical experience would support this as partners of haemodialysis patients have more responsibility and involvement with the dialysis procedure itself than those partners involved with peritoneal dialysis. Lowry et al (1994) also suggests that many patients give over responsibility for their dialysis to their partners. Clinical experience and anecdotal evidence would also support this premise.

There was a significant relationship between depression and anxiety in both the patient and partner groups. That is, if the patient or partner was depressed then they also had a similar level of anxiety.

Dialysis Treatment Modes

Unfortunately a complete comparison across all modes could not be performed. As only 4 subjects out of the 29 were not on home dialysis (that is only 4 patients were on institutionalised dialysis). Most patients who were on in-centre and self-care haemodialysis chose not to participate in this study, and there were a few who were excluded as a result of acute illness at the time of the survey. This may suggest that those patients who dialyse within an institutionalised setting may feel more vulnerable than those on home dialysis.

Results suggest that haemodialysis is more likely to lead to a higher level of depression than CAPD. This could be related to the fact that haemodialysis is more stressful for the patient and partner because of the involvement of complex technologies. When the total BDI scores of haemodialysis patients and their partners were compared results were similar in the nil to moderate categories, but there were more partners
with depression in the moderate to severe range than patients and vice versa in the severe range.

The results from this study do suggest that the levels of anxiety are similar in those patients on haemodialysis and peritoneal dialysis, but there is more anxiety in the partners of those patients on haemodialysis compared to those on peritoneal dialysis. Clinical experience would support this as partners of haemodialysis patients have more responsibility and involvement with the dialysis procedure itself than those partners involved with peritoneal dialysis. Lowry et al (1994) also suggests that many patients give over responsibility for their dialysis to their partners. Clinical experience and anecdotal evidence would also support this premise.

**STUDY OBJECTIVE TWO**

The second objective of this study was to identify any relationship between the incidence of depression and/or anxiety and the severity of renal disease in the two study groups.

**Severity of Renal Disease**

The severity of disease within the sample patient group was much higher than that reported by Craven et al (1991) when comparing overall sample mean scores. This may be explained by the higher mean age of this study’s sample group of 62 years, compared with that of Craven et al (1991) of 50 years. With increasing age an increase in co-morbid conditions can be expected. This view is supported by data
found in Disney (1996). Unfortunately Craven et al (1991) did not report the mean scores within the individual disease categories and so no comparisons could be made with the present study.

The disease categories, which had the highest mean scores were cardiac disease; cerebro-vascular disease; peripheral vascular disease; and access and dialysis events\(^1\). This result is not surprising as it reflects those common co-morbid conditions associated with an increased mortality risk as reported by Disney (1996). Another factor, which may play a role in the higher mean score for this study sample, is that 24.14% of the patient group sample had insulin dependent diabetes mellitus. Diabetes leads to many complications, which includes generalised vascular disease, ESRD and many others. Those patients with ESRD and Diabetes are also more likely to have access related problems especially with vascular access for haemodialysis. The vascular disease which is associated with Diabetes predisposes the haemodialysis patient to have poor native vessels for the formation of a mature and functioning fistula which will supply the needed blood flows (200-300mls/minute) for an effective dialysis. Therefore many Diabetics have graft fistulas formed. Grafts are usually of a synthetic substance ‘Gortex’. These grafts understandably have a greater risk of infection Diabetic person. (Tzamaloukas 1994, 422430).

Relationship between Severity of Renal Disease, Depression and Anxiety

There was no significant relationship demonstrated between the ESRD-SI and BDI, CDI or BAI. These results suggest that there is no relationship between the severity of

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\(^1\) Access and dialysis events refer to problems associated with the access, which is used for dialysis. This may be a vascular access (a fistula, or an intravenous central line), or a peritoneal dialysis catheter into the peritoneum. There are many problems which may occur with access, such as infections, blockages, stenoses in the case of vascular access, and infections, leaks, and blockages in the case of peritoneal dialysis catheters. Dialysis events would include such problems as re-occurring hypotension and angina associated with dialysis therapy.
renal disease and depression or anxiety in the patient or partner group.

There was no significant relationship between the severity of renal disease and haemoglobin, or serum urea levels. However, results do suggest a relationship between depression, anxiety, and serum creatinine levels ($r = .39$ for the full BDI and $r = .46$ for the CDI subset, and $r = .34$ for the BAI). Serum Creatinine level is a marker for dialysis adequacy, and results may suggest that as dialysis efficiency decreases the level of depression increases. This may be related to the increased uraemic effects, which may affect the psychoneuroimmunological functioning of the human body. A cautionary note must be mentioned here. This note refers to the fact that there was no way of accurately assessing when the patients serum creatinine levels were done. That is they may have been collected either pre-dialysis or post dialysis, and which ever was in the majority would have influenced the result. If they were done pre-dialysis the results may reflect an accurate picture, if they were done post-dialysis the result may under estimate the relationship, since post-dialysis serum creatinine levels would be presumably lower as a result of the dialysis procedure.

Neurological Impairment

Long-term dialysis has been associated with neurological dysfunction. This neurological dysfunction was suspected to be due to the effect of uraemia and the possible intake of Aluminium based medications which were used as phosphate binders in the treatment of the calcium and phosphate imbalance which occurs in ESRD. Stewart et al (1979) stated that uraemia affected short term memory, attention span, and alertness detrimentally, but that these effects could be reversed by dialysis. Souheaver et al (1982) also found uraemic patients were impaired on visual alertness, flexible thinking and speed of mental manipulations. Gilli et al (1983)
found that deterioration in memory was related to length of time on dialysis and parathyroid hormone, and that intelligence test performance deteriorated in relation to length of time on dialysis. Results from this study suggest that only 17% of patients have problems with concentration and memory according to the PAS self-report. Clinical experience suggests that this result may be inaccurate, and that the use of the PAS may not be valid or reliable within the ESRD population. Results from this study also suggest that there is quite a significant behaviour change upon the initiation of dialysis. Seventy two per cent of patients had significant behaviour changes occurring to their partners. Those items where the partners scored the patients as having a major change were decreased initiative; increase in demanding and attention seeking behaviour; overly emotional; more irritable; sad or depressed in mood. These behaviour changes may be a reaction to having a chronic illness in which it is vital to rely upon technology for the continuance of life, more so than an indication of possible development of a dialysis associated dementia. Patients also have a very much lower intake in Aluminium based phosphate binders now compared to 15 –20 years ago. All patients (except one who was excluded from the study), passed the Color Form Sorting Test.

Relationship between PAS, Depression, and Anxiety

There was no significant relationship between the PAS, BDI, CDI or BAI in either the patient or partner group. This suggests that the degree of cognitive impairment evidenced did not have a great effect on the levels of depression or anxiety. However, as stated previously results may also indicate that the PAS is not a valid and reliable assessment in the ESRD population.

STUDY OBJECTIVE THREE
The third objective of this study was to identify any correlation between depression and anxiety and the dyadic relationship between the dialysis patient and their partner.

**The Patient and Partner Dyad**

Overall the relationship between the patient and partner were viewed very positively by both. Scores on the DAS were very similar in both patient and partner groups. Both groups scored similarly in both the dyadic consensus and dyadic cohesion items. The partner group views their relationships marginally better than the patients do. Lowry et al (1994) also found that spouses reported few problems with their marriages. This result conflicts markedly with those achieved with the global item score of dyadic satisfaction. On this item the patient group viewed their relationship as much better (92.30% of subjects scored above the patient group mean score), than did the partner group (only 77.30% of subjects scored above the partner group mean score). The results from this item suggest that the partners have an overall poorer level of satisfaction than the patient does, and may also give a better indication of the overall dyadic relationship. This view is supported by work reported by Sharpley and Cross (1982).

These results may also suggest that as a result of the care and support needed by and provided to the patient by their partner due to their chronic illness, the patient perceives their relationship as being better. Clinical experience and anecdotal accounts, suggest the partner does not receive the same level of care and support from the patient that the patient receives from the partner. Rideout et al (1990) results support this view, finding that spouse level of depression increased with a low perception of support from the ill patient. The reported reduction in sexual satisfaction by partners may cause them to feel that they have lost intimacy and
closeness within their relationship.

These results may be influenced by socio-historical factors. That is, many subjects were children during World War II and grew up in the immediate post war period. This was a time of fairly strict social mores in that marriage was regarded as an important basis for family life, and divorce was frowned upon. Anecdotal evidence from clinical experience with dialysis families demonstrates this, with statements from partners such as “I have to do it because he’s my husband” abound in the older age group, whereas they do not occur as frequently in the younger age group.

The overall impression of the transcribed responses to the five-minute speech samples was that the patients are well satisfied with their relationships, but there is a pervasive sadness in those of the partners. This is supported by the poorer ‘happiness’ score on the DAS by the partners. This may result from the perceived losses to the partner by dialysis, and to the significant changes in lifestyle which occurs as a consequence of home dialysis. This view is supported by those works by Lowry et al (1994), Burton et al (1988), and Dunn et al (1994). This decreased satisfaction may also be as a result of the possible use of denial by the patients regarding the impact of their problems on those who surround them (Kaplan De-Nour 1982).

The partners reported that the patient is less critical of them, which may suggest that the patients are very reliant upon their partner for assistance and support with dialysis. The partners also reported they are less critical of the patient, which may result from many factors including feelings of guilt and socio-historical factors.

**STUDY OBJECTIVE FOUR**

The sixth study objective of this study was to identify any relationship between
depression and anxiety and the individual’s perception of their own health

Perception of Illness

Patients

The results of the MOS SF-36 indicate that the patient group views their own health markedly below that of the general USA population. The results are further below various age groups investigated by Ware (1993) during the development phase of the MOS SF-36. The patient group scores were below those of the oldest population tested in the USA (65-74 age group). The patient group scored markedly lower in all categories of the MOS SF-36.

The MOS SF-36 score (all categories) was significantly correlated with the BDI, CDI, and BAI. The mental health category was significantly correlated with the BDI (r = .67, p < 0.00), the CDI (r = .63, p < 0.00) and the BAI (r = .62, p < 0.00). There was a negative correlation between the MOS SF-36 scores and levels of depression and anxiety.

The overall results suggest that the individual’s perception of their health by way of the self-report MOS SF-36, may be a more accurate indication of the patient’s health status than the other instruments used in this study. The physical categories (physical functioning, physical role, bodily pain, general health, and vitality) are perceived to be much worse than those in the emotional and mental health categories. This may suggest that what Scribner said in 1964 (Levy 1996, 678) may still be true of today. Although dialysis has improved markedly to the present day compared to the time of Scribner. It may be that patients on dialysis are still fighting for survival by getting
through each day and their emotional responses are being suppressed as a result. It could also be suggested that they may be using denial of their mental and emotional state as people still view mental health problems as stigmatised.

Overall, results from this present study suggest that the physical limitations, which have resulted from ESRD, have more of an impact than emotional and mental health problems. The restrictions enforced by the dialysis procedure are superimposed with those of the physical limitations and fatigue lead to severe lifestyle changes for both the patient and their partner.

These views were also supported by the results from the transcriptions from the patient responses to the five-minute speech samples. Again physical limitations were a major concern to the patients.

Partners

The scores attained by the partner group are comparable with those of the USA age group of 65-74 years. This is supported by the mean age group of the partners of 67.93 years of those aged > 60 years. Therefore the results suggest that the partner’s have a realistic view of their health and it is similar to their age group.

However it may be true that partners could have compared their health to that of the patient’s and so have given more positive evaluations (a ‘halo effect’) due to being confronted with their partner’s obvious health problems.
CONCLUSION

This study investigated the dialysis patient and partner dyad in connection to the psychological impact dialysis has made on them. Depression and anxiety are well recognised reactions within the dialysis patient and to a lesser degree in the dialysis partner. The degree to which depression and anxiety has been influenced by factors such as neurological impairment, the patient/partner dyadic relationship, severity of renal disease, and the individual’s perception of their illness had not been investigated in one study before. The results of this study have been presented within a comprehensive biopsychosocial model, and have presented a uniquely Australian perspective. A cross-sectional descriptive comparative study design was used.

The results of the study failed to support the null hypotheses. There was a significant incidence of depression and anxiety in the patients and their partners, and there were relationships between the independent and dependent variables.

Limitations to this study included the small sample, although the sample is comparative with other studies, which have used single dialysis centres. Future studies should implement a strategy, which would enable people who are non-English speaking to participate. Dialysis patients and partners from other cultural backgrounds would provide further insights into the impact of dialysis, both the positive and the negative implications. The results from this study have emphasised the difficulty in differentiating depression as a definitive psychiatric disorder from that of a reactive dysphoric mood state as a result of a chronic illness such as end-stage renal disease.

The results from this study present a maiden voyage into the patient and partner dyad and the impact dialysis has made upon them. Further research needs to be
undertaken into this field and to possibly explore the 'dialysis family' in greater
detail. This study has presented findings, which are thought provoking, and provides
initial direction for future research into the effects of long term life-sustaining
technology. Dialysis is unique in this area, as it does not provide a cure for end-stage
renal disease. Dialysis presents an ethical dilemma, as it can be argued that dialysis
prolongs death as opposed to prolonging life. Depression in the dialysis population
may also be related to different biochemical and hormonal imbalances, which occur
as a result of end-stage renal disease. Future research should investigate dialysis
adequacy and its relationship to the incidence of depression and anxiety.
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DEAR ...........................................................

Currently I am enrolled as a student at The University of Wollongong, and am undertaking a Masters in Nursing Program.

This research is into the effects of long term dialysis on the person who is on dialysis and their partner. During my many years of caring for people on dialysis I have noticed that dialysis is stressful for both the person on dialysis and their partner. As a result of this I would like to investigate what effects long term dialysis has on your life - in particular feelings of anxiety and depression; and the effects of the dialysis on the relationship between the person on dialysis and their dialysis partner (i.e., the person who helps with the dialysis).

I would like to invite you to participate in this research project. The results of this research may lead to the development of priorities and guidelines for the care of people on dialysis. Your involvement would be participating in an interview with myself. During this interview you will be asked specific questions, and it is envisaged that the interview will be approximately 1 hour in length. Please find attached a consent form. If you are willing to participate in this research project, would you please complete the form and place it in the envelope supplied. This envelope can than either be posted, or left in the Renal Unit at the Wollongong Hospital (please ensure envelope is sealed), and I will collect them from there.

You are free to withdraw from the research at any time.

If you have any enquiries regarding the conduct of the research please contact myself on 044 217622 or, the Secretary of the University of Wollongong Human Research Ethics Committee on (042) 214457.

I look forward to your help with this research project, as the success of this project is reliant upon your participation.

Thank you for your assistance.

Yvonne White

Dr B. Grenyer (Research Project Supervisor)
CONSENT FORM

ILLAWARRA DIALYSIS SURVEY

YVONNE WHITE
(Researcher)

This research project is being conducted as part of a Master of Nursing program. This project is supervised by Dr Brin Grenyer in the Department of Nursing at the University of Wollongong.

You are invited to participate in this research project which will be investigating how you, and your dialysis partner feel in regard to dialysis. To be able to gain the information required it will be necessary to interview you and your partner separately. The interview will take approximately one (1) hour for each of you and will require you to answer three questionnaires (the BDI, BAI, and DAS). Each questionnaire is identified only by a code number and will in no way identify you to ensure anonymity of responses.

The results of this research may lead to the development of priorities and guidelines for the care of people on dialysis.

If you agree to be a participant in this research project the researcher will contact you by phone to organise a day and time for the interview. This interview will be conducted in your own home if you agree, or can be arranged somewhere else. Your participation is very important to the success of this project.

All completed questionnaires are held in a secure place and confidentiality will be maintained.

Your participation in this project is entirely separate from any treatment you are receiving, and will in no way jeopardise medical treatment. (You are free to withdraw from the research at any time without affecting the treatment you receive.)

If you have any enquires regarding the conduct of the research please contact the Secretary of the University of Wollongong Human Research Ethics Committee on (042) 214457.

If you wish to take part in this research project, please sign below.

I understand that the data collected will be used for this research project purposes only and I consent for the data to be used in that manner.

(Signature):..............................................................................(Date):...........................................

Are you a dialysis patient, or a dialysis partner?..........................................................................

Consent
1. Age:  
2. Sex:  

3. Where were you born?  
   Australia □  
   Other □  

4. Do you speak another language at home (other than English)?  
   Yes □  
   No □  

5. Marital Status:  
   □ single  
   □ defacto  
   □ married  
   □ widowed  
   □ divorced  

6. Number of living children:........  

7. Education  
   Number of years of education  
   □ HSC  
   □ Trade Certificate/Qualification .................................................  
   □ Tertiary Qualification ...............................................................  
   □ Other .................................................................  

8. Occupation:  
   (or previous occupation if retired)  

9. Hours worked per week currently?  

10. Annual family Income
SECTION ONE  MEDICAL HISTORY

11. Primary Renal diagnosis: 

12. Latest Haemoglobin, Serum Creatinine and Urea:  
   Hb. 
   Creat. 
   Urea 
   Kt/V 

13. Is patient on renal transplant list?  
   Yes  
   No 

14. Has patient had any renal transplants?  
   Yes  
   No 

15. Current medications: 

SECTION TWO  DIALYSIS HISTORY

16. Number of years on dialysis: 

17. Mode of current dialysis therapy: 

18. Has there been any change in dialysis therapy mode?:  
   YES  
   NO 

19. Reason for dialysis therapy change: 

Place of Interview: 

Date and Time of interview: 

**SECTION ONE: DEMOGRAPHIC DETAILS - Partner**

1. Age: 
   
2. Sex: 
   
3. Where were you born? 
   - Australia □
   - Other □

4. Do you speak another language at home (other than English)?
   - Yes □
   - No □

5. Marital Status: 
   - single □
   - defacto □
   - married □
   - widowed □
   - divorced □

6. Number of living children: 
   
7. Education
   - Number of years of education 
   - HSC □
   - Trade Certificate/Qulification (…………………………………………………………)
   - Tertiary Qualification (…………………………………………………………………)
   - Other (…………………………………………………………………………………)

8. Occupation: 
   (or previous occupation if retired) 
   
9. Hours worked per week currently? 
   
10. Annual Family Income
   

11. What is your relationship to the person on dialysis (use patient's name)?

- Spouse
- Mother
- Relative: _______________
- Other: _______________

12. Do you have any medical conditions:

13. Are you taking any medications at the present? If yes, what are they?
APPENDIX C
The responses to this question will be audio-taped.

1. Instructions for Five Minute Speech Sample:

The participant will be given the following standard, verbal introduction to the task:

"When I ask you to begin, I would like you to speak for five minutes, telling me what kind of a person (dialysis partner's or patient's name) is and how you get along together. After you have begun to speak, I would prefer not to answer and questions until the five minutes are over.

Do you have any questions you would like to ask before we begin?

2. Instructions for five minute Speech Sample:

The participant will be given the following standard, verbal introduction to the task:

"I would like you to talk to me for a few minutes about your life at the moment - the good things and the bad - what it is like for you. Once you have started I shall be here listening to you but I would rather not reply to any questions you may have until a five minute period is over."
COGNITION
(Patient self responses)

Now let me ask you a few questions to check your concentration and your memory. Most of them will be easy.

I am going to name three objects. After I have said them I want you to repeat them. Remember what they are, because I am going to ask you to name them in a few minutes.

'Apple'  'Table'  'Penny'

Could you repeat the three items for me?

Repeat objects until all three are learned. Stop after five unsuccessful attempts.

1. I am going to give you a piece of paper. Would you please write any complete sentence on that piece of paper for me?

   If sentence is illegible, ask "Could you read it for me?", and copy sentence onto sheet

   Sentence should have a subject and a verb, and make sense.
   Spelling and grammatical errors are acceptable.
   Correct
   Incorrect or refusal
   Not asked (e.g. sensory or motor impairment)

2. Now what were the three objects I asked you to remember?

   Score 1 for each remembered, 0 if an error is made because object is not mentioned or subject refuses. Order of recall is not important.

   Apple
   Object not mentioned or subject refuses
   Not asked (e.g. sensory or motor impairment)

   Table
   Object not mentioned or subject refuses
   Not asked (e.g. sensory or motor impairment)

   Penny
   Object not mentioned or subject refuses
   Not asked (e.g. sensory or motor impairment)

Please listen carefully to the following name and address, then repeat it:

   John Brown, 42 West Street, Kensington

Repeat address until learned. Stop after five unsuccessful attempts.

Please go on remembering this name and address and I will ask you about it later.

3. I am now going to say the names of some people who were famous and I would like you to tell me who they were or why they were famous in the past.
Score 0 for each person correctly identified, 1 if answer is incorrect or subject refuses.

a. Charlie Chaplin  
   (actor, comedian, film star, comic)  
   b. Incorrectly identified or refused  
   c. Not asked (e.g. sensory or motor impairment)

a. Joseph Stalin  
   (Soviet, Russian, W.W.II leader, Communist Leader)  
   b. Incorrectly identified or refused  
   c. Not asked (e.g. sensory or motor impairment)

a. Captain Cook  
   (explorer, sailor, navigator, discoverer)  
   b. Incorrectly identified or refused  
   c. Not asked (e.g. sensory or motor impairment)

a. Adolf Hitler  
   (German, Nazi, WWII leader,)  
   b. Incorrectly identified or refused  
   c. Not asked (e.g. sensory or motor impairment)

4. New years day falls on what date?  
   A. First of January/first day of the new year  
   b. A wrong date, does not know, refusal  
   c. Not asked

5. What is the name and address I asked you to remember a short time ago?  
   Score 0 for each person correctly identified, 1 if a component is not mentioned or subject refuses.  
   Order of recall is not important.

   A. John  
      b. Component not mentioned or subject refuses  
      c. Not asked (e.g. sensory or motor impairment)

   A. Brown  
      b. Component not mentioned or subject refuses  
      c. Not asked (e.g. sensory or motor impairment)

   A. 42  
      b. Component not mentioned or subject refuses  
      c. Not asked (e.g. sensory or motor impairment)

   A. West Street  
      b. Component not mentioned or subject refuses  
      c. Not asked (e.g. sensory or motor impairment)

   A. Kensington  
      b. Component not mentioned or subject refuses  
      c. Not asked (e.g. sensory or motor impairment)

6. Here is a drawing. Please make a copy of it here.
   Hand subject the paper with 2 five-sided figures and point to the space underneath it.
   Correct if 2 five-sided figures intersect to make a four sided figure.
7. Read aloud the words on this page and then do what it says. 
Hand subject the sheet with the words “close your eyes”.
A. Correct (subject closes eyes)
b. Incorrect, refusal
c. Not asked (e.g. sensory or motor impairment)

8. Now, read aloud the words on this page and do what it says. 
Hand subject the sheet with the words “cough hard”.
A. Correct (subject coughs)
b. Incorrect, refusal
c. Not asked (e.g. sensory or motor impairment)

9. Tell me what objects you see in this picture?
Hand the four-object sheet to the subject.
Score 0 for each object identified, 1 if an object is not mentioned or subject refuses. 
Order of identification is not important.
A. Teapot/kettle 
b. Object not mentioned or subject refuses 
c. Not asked (e.g. sensory or motor impairment)

A. Telephone (whole object not just dial) 
b. Object not mentioned or subject refuses 
c. Not asked (e.g. sensory or motor impairment)

A. Scissors 
b. Object not mentioned or subject refuses 
c. Not asked (e.g. sensory or motor impairment)

A. Fork 
b. Object not mentioned or subject refuses 
c. Not asked (e.g. sensory or motor impairment)

That brings us to the end of the interview. Thank you very much for your time.
BEHAVIOURAL CHANGES
(Partner responses regarding patient)

I would like to ask you about some specific situations and whether SUBJECT'S memory has become any worse in these areas compared to earlier life.

1. Has s/he recently had any difficulty finding his/her way around familiar places when alone?
   (Where s/he lives, the neighbourhood and shops, the homes of close friends and relatives?)
   a. No difficulty, or doesn't think so
   b. Moderate or occasional difficulty
   c. Bedridden, immobile
   d. Does not know

2. Does SUBJECT have more trouble remembering things that have happened recently?
   a. No, not much worse
   b. A bit worse
   c. Yes, a lot worse
   d. Does not know

3. Is SUBJECT worse at remembering where belongings are kept?
   a. No, not much worse
   b. A bit worse
   c. Yes, a lot worse
   d. Does not know

4. Does s/he have more trouble recalling conversations a few days later?
   a. No, not much worse
   b. A bit worse
   c. Yes, a lot worse
   d. Does not know

5. Does s/he have more trouble remembering appointments and social arrangements?
   a. No, not much worse
   b. A bit worse
   c. Yes, a lot worse
   d. Does not know

6. Does s/he have more trouble recognising the faces of family and close friends even though s/he has reasonably good vision?
   a. No, not much worse
   b. A bit worse
   c. Yes, a lot worse
   d. Does not know

7. Does s/he need help to handle her/his money and financial affairs (banking, paying bills, deciding how and where to spend money, or how to invest)?
   A. No, no difficulty
   b. Yes, but manages day to day purchases
   c. Yes, cannot manage finances or handle money
   d. Has never handled finances except for day to day purchases
   c. Does not know

8. Has SUBJECT had more trouble concentrating recently?
   A. No
   b. Depends on situation
   c. Yes
   d. Does not know

9. Recently have her/his thoughts seemed more mixed up so that s/he cannot get them sorted out?
   A. No more than usual
   b. Depends on situation
   c. Yes
   d. Does not know

10. Recently, has SUBJECT had more difficulty making decisions?
    A. No more than usual (includes makes no decisions)
    b. Depends on situation
Here are some more questions concerning SUBJECT'S behavior.

11. Is SUBJECT lacking in initiative?
   A. No
   B. Yes → Is this a change from earlier?
      No
      Yes
      Does not know
   C. Does not know

12. Is SUBJECT demanding and attention seeking?
   A. No
   B. Yes → Is this a change from earlier?
      No
      Yes
      Does not know
   C. Does not know

13. Is/he overly emotional?
   A. No
   B. Yes → Is this a change from earlier?
      No
      Yes
      Does not know
   C. Does not know

14. Does s/he like mixing with others?
   A. No
   B. Yes → Is this a change from earlier?
      No
      Yes
      Does not know
   C. Does not know

15. Is s/he apathetic and withdrawn?
   A. No
   B. Yes → Is this a change from earlier?
      No
      Yes
      Does not know
   C. Does not know

16. Is s/he irritable?
   A. No
   B. Yes → Is this a change from earlier?
      No
      Yes
      Does not know
   C. Does not know

17. Is s/he a person who’s easy to get on with?
   A. No
   B. Yes → Is this a change from earlier?
      No
      Yes
      Does not know
   C. Does not know

18. Is s/he impatient and always wanting things right away?
   A. No
   B. Yes → Is this a change from earlier?
      No
      Yes
      Does not know
19. Is s/he suspicious of others?
   A. No
   b. Yes → Is this a change from earlier?
      No
      Yes
      Does not know
   c. Does not know

20. Is s/he inflexible so that s/he won’t change her/his ways even when it’s necessary?
   A. No
   b. Yes → Is this a change from earlier?
      No
      Yes
      Does not know
   c. Does not know

21. Is s/he cantankerous?
   A. No
   b. Yes → Is this a change from earlier?
      No
      Yes
      Does not know
   c. Does not know

22. Is s/he particularly sad in mood or depressed?
   A. No
   b. Yes → Is this a change from earlier?
      No
      Yes
      Does not know
   c. Does not know

23. Does s/he keep her/himself looking reasonably clean and respectable without having to be reminded?
   A. Yes
   b. Only sometimes → Is this a recent change from what s/he was like earlier in life?
      No, is worse now
      Yes
      Does not know
   c. No, needs constant care
   d. Does not know

24. Does s/he tend to act without considering other people’s feelings?
   A. Yes
   b. Only sometimes → Has s/he always been like this?
      No, is worse now
      Yes
      Does not know
   c. Most of the time
   d. Does not know

25. Does s/he behave on social occasions or in public in a way which can make people embarrassed or upset?
   A. Yes
   b. Occasionally → Is this a recent change from what s/he was like earlier in life?
      No, is worse now
      Yes
      Does not know
   c. Very often
   d. Does not know

That brings us to the end of the interview. Thank you very much for your time.
COGNITIVE DECLINE SCORE (CD)
Add boxes 1 to 10 = CD
Number of ?'s =
If ? is not zero, score should be pro-rated using formulae

\[ 10 \times \frac{CD}{10} - ? = CD \]

BEHAVIOUR CHANGE (B)
Add boxes 11 to 25 = (B)
Number of boxes with ?'s =
If ? is not zero, score should be pro-rated using formulae

\[ 15 \times \frac{B}{15} - ? = (B) \]
COLOR FORM SORTING TEST
Weigl-Goldstein-Scheerer
RECORD FORM

Name __________________________ Sex _____ Age _____ Date __________________
Examiner ________________________

REFERENCE


MATERIALS

Twelve Blocks: Four colors (red, yellow, green, blue) in each of three forms (triangle, square, circle).

DIRECTIONS FOR ADMINISTRATION

Ascertain that the subject is not color blind. Use the Ishihara Test or any other simple test of color naming. Do not use the materials of this test.

Subject is presented with the twelve figures in random order, and instructed: “Sort those figures which you think belong together,” or, “Put those together which you think can be grouped together.” Variations of the wording are permissible if subject does not appear to understand. If the subject asks any questions as to how to group the figures, answer, “That is entirely up to you.” Record verbatim, all conversation between examiner and subject, as well as his spontaneous talking. The sorting is sketched in the spaces provided in this Record Form.

SUMMARY

Summary of Subject’s Verbal Explanation

<table>
<thead>
<tr>
<th>Experiment</th>
<th>Form</th>
<th>Color</th>
<th>Mixed Form &amp; Color</th>
<th>Pattern</th>
<th>Form Pattern</th>
<th>Color Pattern</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Make an X in a box which describes how the subject sorted these blocks.</td>
<td>I</td>
<td>II</td>
<td>IIIa</td>
<td>IIb(I)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Make a circle around an X if the subject’s explanation correctly describes his sorting.</td>
<td>IIIb(II)</td>
<td>IIIc</td>
<td>IIId(I)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IIId(II)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Accept (__) Reject (___)

RESULTS

Make an X to mark Pass or Fail. Make a circle around an X if the subject’s explanation fits his sorting, regardless of whether or not the sorting itself was the one expected.

Passed Failed

Exp. I and II (S. can sort and shift method of sorting voluntarily) _____ _____
Exp. IIIa and b (S. learned to shift from color to form) _____ _____
Exp. IIIc (S. accepted other groupings than his own) _____ _____
Exp. IIId (S. learned to shift from form to color) _____ _____

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EXPERIMENT I, SORTING

Make a graphic record in the space below of the arrangement of all the twelve figures by the subject. (See illustrations, pp. 119-122, in monograph.) Attention should be paid to possible pattern-building by the subject.

After the subject has completed his grouping, ask, "Why have you grouped them that way?" or "Why do they belong together?" or "Why do they belong this way?" Record answer below.

EXPERIMENT II, VOLUNTARY SHIFTING

Tell the subject, "Now put the figures together in another way," or "in a different way." Record the grouping graphically, as in experiment I. After completion inquire, as in experiment I, as to reasons for grouping in a particular fashion.
EXPERIMENT III, INDUCED SHIFTING
- From FORM to COLOR -

IIIc

If the subject grouped in experiment I according to form, and was unable to shift to color grouping in experiment II, present the subject with the proper color groupings and ask him, "Does this make sense to you?" or "Can we put them together this way too?" Acceptance or rejection is recorded as in experiment I. Find out if the subject knows why the blocks can be sorted thus.

IIId

If the subject accepts the color grouping in IIIc, reshuffle the figures and repeat experiments I and II in order to determine whether he has now learned to shift from form to color. Record below under IIId (I) and IIId (II).

IIId (I)

IIId (II)
EXPERIMENT III, INDUCED SHIFTING
- From COLOR to FORM -

IIIa

If the subject grouped in experiment I according to color, and was unable to shift to form grouping in experiment II, turn the figures with their neutral (back) sides up, and tell the subject, "Sort those figures which you think belong together," etc., as in experiment I. Make graphic recordings of arrangement and inquire for reasons as in experiment I.

IIIb

If the subject has now grouped according to form, turn the figures back again to the colored sides, and repeat the procedures of experiments I and II, in order to determine whether the subject has learned to shift from color to form. Record below under IIIb (I) and IIIb (II).

IIIb (I)

IIIb (II)
J. Craven and others

END: PAGN  RENAL DISEASE SEVERITY INDEX (ESRD-SI)

rate the severity of organic disease(s) as you have determined are present in this patient at the present time. Guided by the guidelines provided, assign an individual rating for each of the following disease categories by placing a single mark (✓) on each of the indicated spaces. Place a mark in the absent column if the disease is absent. Ratings should be based on the nature of the underlying disease and should be independent of the subjective reactions of the patient to the disease.

<table>
<thead>
<tr>
<th>Category</th>
<th>Disease</th>
<th>Severity rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Absent</td>
<td>Mild</td>
<td>Moderate</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Severe</td>
</tr>
<tr>
<td></td>
<td>e.g.: occasional angina of effort</td>
<td>e.g.: angina with or without CHF</td>
</tr>
<tr>
<td>Absent</td>
<td>Mild</td>
<td>Moderate</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Severe</td>
</tr>
<tr>
<td></td>
<td>e.g.: occasional evidence of TIA or amaurosis fugax</td>
<td>e.g.: recurrent TIA</td>
</tr>
<tr>
<td>Absent</td>
<td>Mild</td>
<td>Moderate</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Severe</td>
</tr>
<tr>
<td></td>
<td>e.g.: occasional pain on exercise</td>
<td>e.g.: pain with mild activity i.e.: walking half a block</td>
</tr>
<tr>
<td>Absent</td>
<td>Mild</td>
<td>Moderate</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Severe</td>
</tr>
<tr>
<td></td>
<td>e.g.: paresthesiae</td>
<td>e.g.: sensory changes</td>
</tr>
<tr>
<td>Absent</td>
<td>Mild</td>
<td>Moderate</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Severe</td>
</tr>
<tr>
<td></td>
<td>e.g.: minimal symptoms, biochemical + radiological changes</td>
<td>e.g.: bone pain consistently present, radiological changes obvious</td>
</tr>
<tr>
<td>Absent</td>
<td>Mild</td>
<td>Moderate</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Severe</td>
</tr>
<tr>
<td></td>
<td>e.g.: SOB with exertion periodic bronchitis</td>
<td>e.g.: SOB with mild exercise, frequent respiratory infections</td>
</tr>
<tr>
<td>Absent</td>
<td>Mild</td>
<td>Moderate</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Severe</td>
</tr>
<tr>
<td></td>
<td>e.g.: vision not as clear as previously, unable to see fine detail, can read with slight strain</td>
<td>e.g.: no longer able to drive car secondary to vision loss, able to read large print only with magnifiers</td>
</tr>
<tr>
<td>Absent</td>
<td>Mild</td>
<td>Moderate</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Severe</td>
</tr>
<tr>
<td></td>
<td>e.g.: nausea, feelings of weakness post-dialysis</td>
<td>e.g.: nausea, vomiting, occasional syncope</td>
</tr>
<tr>
<td>Absent</td>
<td>Mild</td>
<td>Moderate</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Severe</td>
</tr>
<tr>
<td></td>
<td>e.g.: occasional malplacement, easily correctable</td>
<td>e.g.: peritonitis, catheter infection, poor flow</td>
</tr>
</tbody>
</table>
The ESRD-SI

Scoring

Each disease category on the ESRD-SI may be rated 'absent' or on a five-point severity scale. The minimum score for each category is zero, the maximum score 10. The scores for each possible rating are weighted according to the criteria described in the methods and assigned as follows to each category: heart disease (0, 3, 5, 6, 8, 10); cerebral vascular disease (0, 5, 6, 7, 8, 9); peripheral vascular disease (0, 3, 4, 5, 7, 8); peripheral neuropathy (0, 2, 3, 4, 5, 7); bone disease (0, 1, 3, 5, 7, 8); respiratory disease (0, 3, 5, 6, 8, 10); visual impairment (0, 2, 4, 5, 6, 8); autonomic neuropathy and gastrointestinal disease (0, 2, 4, 5, 7, 8); access and dialysis events (0, 1, 4, 6, 7, 9); diabetes (0, 1, 3, 5, 7, 9); and other (0, 1, 2, 4, 6, 8). The ESRD-SI index score is the sum total of the individual disease category scores.
Which one of the statements in each group best describes the way you have been feeling in the past week including today.

1. a. I do not feel sad.
   b. I feel sad.
   c. I am sad all the time and I can't snap out of it.
   d. I am so sad or unhappy that I can't stand it.

2. a. I am not particularly discouraged about the future
   b. I feel discouraged about the future.
   c. I feel I have nothing to look forward to.
   d. I feel that the future is hopeless and that things cannot improve.

3. a. I do not feel like a failure.
   b. I feel I have failed more than the average person.
   c. As I look back on my life, all I can see is a lot of failures.
   d. I feel I am a complete failure as a person.

4. a. I get as much satisfaction out of things as I used to.
   b. I don't enjoy things the way I used to.
   c. I don't get real satisfaction out of anything any more.
   d. I am dissatisfied or bored with everything.

5. a. I don't feel particularly guilty.
   b. I feel guilty a good part of the time.
   c. I feel quite guilty most of the time.
   d. I feel guilty all of the time.

6. a. I don't feel I am being punished.
   b. I feel I may be punished.
   c. I expect to be punished.
   d. I feel I am being punished.

7. a. I don't feel disappointed in myself.
   b. I am disappointed in myself.
   c. I am disgusted with myself.
   d. I hate myself.

8. a. I don't feel worse than anybody else.
   b. I am critical of myself for my weaknesses or mistakes.
   c. I blame myself all the time for my faults.
   d. I blame myself for everything bad that happens.

9. a. I don't have any thoughts of killing myself.
   b. I have thoughts about killing myself, but I would not carry them out.
   c. I would like to kill myself.
   d. I would kill myself if I had the chance.

10. a. I don't cry any more than usual.
    b. I cry more now than I used to.
    c. I cry all the time now.
    d. I used to be able to cry, but now I can't cry even though I want to.

11. a. I am no more irritated now than I ever am.
    b. I get annoyed or irritated more easily than I used to.
    c. I feel irritated all the time now.
    d. I don't get irritated at all by the things that used to irritate me.

12. a. I have not lost interest in other people.
    b. I am less interested in other people than I used to be.
    c. I have lost most of my interest in other people.
I have lost all of my interest in other people.

13. a. I make decisions about as well as I ever could.
   b. I put off making decisions more than I used to.
   c. I have greater difficulty in making decisions than before.
   d. I can't make decisions at all anymore.

14. a. I don't feel I look any worse than I used to.
    b. I am worried that I am looking old or unattractive.
    c. I feel that there are permanent changes in my appearance that make me look unattractive.
    d. I believe that I look ugly.

15. a. I can work about as well as before.
    b. It takes an extra effort to get started at doing something.
    c. I have to push myself very hard to do anything.
    d. I can't do any work at all.

16. a. I can sleep as well as usual.
    b. I don't sleep as well as I used to.
    c. I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
    d. I wake up several hours earlier than I used to and cannot get back to sleep.

17. a. I don't get more tired than usual.
    b. I get tired more easily than I used to.
    c. I get tired from doing almost anything.
    d. I am too tired to do anything.

18. a. My appetite is no worse than usual.
    b. My appetite is not as good as it used to be.
    c. My appetite is much worse now.
    d. I have no appetite at all anymore.

19. a. I haven't lost much weight, if any, lately.
    b. I have lost more than 2 kilograms (5 pounds).
    c. I have lost more than 4 kilograms (10 pounds).
    d. I have lost more than 6 kilograms (15 pounds).

   I am purposely trying to lose weight by eating less.  Yes  No

20. a. I am no more worried about my health than usual.
    b. I am worried about physical problems such as aches and pains; or upset stomach; or constipation.
    c. I am very worried about physical problems and its hard to think of much else.
    d. I am so worried about my physical problems that I cannot think about anything else.

21. a. I have not noticed any recent change in my interest in sex.
    b. I am less interested in sex than I used to be.
    c. I am much less interested in sex now.
    d. I have lost interest in sex completely.
Below is a list of common symptoms of anxiety. Please read each item in the list carefully. Indicate how much you have been bothered by each symptom during the PAST WEEK, INCLUDING TODAY by placing an X in the corresponding column next to each symptom.

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Mildly it did not bother me much</th>
<th>Moderately it was very unpleasant but I could stand it</th>
<th>Severely I could barely stand it</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Numbness or tingling</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>Feeling hot</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>Wobbliness in legs</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>4.</td>
<td>Unable to relax</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>5.</td>
<td>Fear of the worst happening</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>6.</td>
<td>Dizzy or light-headed</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>7.</td>
<td>Heart pounding or racing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>Unsteady</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>Terrified</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>Nervous</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>11.</td>
<td>Feelings of choking</td>
<td></td>
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<tr>
<td>12.</td>
<td>Hands trembling</td>
<td></td>
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<tr>
<td>13.</td>
<td>Shaky</td>
<td></td>
<td></td>
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<tr>
<td>14.</td>
<td>Fear of losing control</td>
<td></td>
<td></td>
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<tr>
<td>15.</td>
<td>Difficulty breathing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td>Fear of dying</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>17.</td>
<td>Scared</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18.</td>
<td>Indigestion or discomfort in abdomen</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19.</td>
<td>Faint</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20.</td>
<td>Face flushed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21.</td>
<td>Sweating (not due to heat)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
• Relationships •

How often would you say the following events occur between you and your mate? (Circle one option)

- Calmly discuss something
  - Never
  - Less than once a month
  - Once or twice a month
  - Once or twice a week
  - Once a day
  - More often

- Work together on a project
  - Never
  - Less than once a month
  - Once or twice a month
  - Once or twice a week
  - Once a day
  - More often

- Have a stimulating exchange of ideas
  - Never
  - Less than once a month
  - Once or twice a month
  - Once or twice a week
  - Once a day
  - More often

Most persons have disagreements in their relationships. Please indicate below the approximate extent of agreement or disagreement between you and your partner for each item on the following list: (Circle one option)

- Amount of time spent together
  - Always Agree
  - Almost Always Agree
  - Occasionally Disagree
  - Frequently Disagree
  - Almost Always Disagree
  - Always Disagree

- Aims, goals, and things believed important
  - Always Agree
  - Almost Always Agree
  - Occasionally Disagree
  - Frequently Disagree
  - Almost Always Disagree
  - Always Disagree

- Philosophy of Life
  - Always Agree
  - Almost Always Agree
  - Occasionally Disagree
  - Frequently Disagree
  - Almost Always Disagree
  - Always Disagree

The dots on the following line represent different degrees of happiness in your relationship. The middle point, "happy", represents the degree of happiness of most relationships.

• Please circle the dot which best describes the degree of happiness, all things considered, of your relationship -

<table>
<thead>
<tr>
<th>Perfect</th>
<th>Extremely Happy</th>
<th>Very Happy</th>
<th>Happy</th>
<th>A Little Unhappy</th>
<th>Fairly Unhappy</th>
<th>Extremely Unhappy</th>
</tr>
</thead>
</table>

How critical is your partner of you? (Circle one number)

1 2 3 4 5 6 7 8 9 10

Not at all Critical Average Very Critical indeed

How critical are you of your partner? (Circle one number)

1 2 3 4 5 6 7 8 9 10

Not at all Critical Average Very Critical indeed
APPENDIX J
INSTRUCTIONS: This questionnaire asks for your views about your health, how you feel and how well you are able to do your usual activities.

Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is:
   - Excellent
   - Very good
   - Good
   - Fair
   - Poor
   (circle one)

2. Compared to one year ago, how would you rate your health in general now?
   - Much better now than one year ago
   - Somewhat better now than one year ago
   - About the same as one year ago
   - Somewhat worse now than one year ago
   - Much worse now than one year ago
   (circle one)
3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

<table>
<thead>
<tr>
<th>ACTIVITIES</th>
<th>Yes Limited A Lot</th>
<th>Yes Limited A Little</th>
<th>No, Not Limited At All</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>c. Lifting or carrying groceries</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>d. Climbing several flights of stairs</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>e. Climbing one flight of stairs</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>f. Bending, kneeling, or stooping</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>g. Walking more than one kilometre</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>h. Walking half a kilometre</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>i. Walking 100 metres</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>j. Bathing or dressing yourself</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Cut down on the amount of time you spent on work or other activities</td>
<td>1</td>
</tr>
<tr>
<td>b. Accomplished less than you would like</td>
<td>1</td>
</tr>
<tr>
<td>c. Were limited in the kind of work or other activities</td>
<td>1</td>
</tr>
<tr>
<td>d. Had difficulty performing the work or other activities (for example, it took extra effort)</td>
<td>1</td>
</tr>
</tbody>
</table>
During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

(circle one number on each line)

<table>
<thead>
<tr>
<th></th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Cut down on the amount of time you spent on work or other activities</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>b. Accomplished less than you would like</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>c. Didn’t do work or other activities as carefully as usual</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

(circle one)

Not at all 1
Slightly 2
Moderately 3
Quite a bit 4
Extremely 5

7. How much bodily pain have you had during the past 4 weeks?

(circle one)

No bodily pain 1
Very mild 2
Mild 3
Moderate 4
Severe 5
Very severe 6
During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework?)

(circle one)

- Not at all
- A little bit
- Moderately
- Quite a bit
- Extremely

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

(cycle one number on each line)

<table>
<thead>
<tr>
<th>Question</th>
<th>All of the Time</th>
<th>Most of the Time</th>
<th>A Good Bit of the Time</th>
<th>Some of the Time</th>
<th>A Little of the Time</th>
<th>None of the Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Did you feel full of life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>b. Have you been a very nervous person?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>c. Have you felt so down in the dumps that nothing could cheer you up?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>d. Have you felt calm and peaceful?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>e. Did you have a lot of energy?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>f. Have you felt down?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>g. Did you feel worn out?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>h. Have you been a happy person?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>i. Did you feel tired?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>
10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc)?

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

11. How TRUE or FALSE is each of the following statements for you?

<table>
<thead>
<tr>
<th>Statement</th>
<th>Definitely True</th>
<th>Mostly True</th>
<th>Don't Know</th>
<th>Mostly False</th>
<th>Definitely False</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. I seem to get sick a little easier than other people</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>b. I am as healthy as anybody I know</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>c. I expect my health to get worse</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>d. My health is excellent</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
Table K.1
CORRELATION BETWEEN ASSESSMENT INSTRUMENTS FOR THE PATIENT SUBJECT GROUP
(n = 29)

<table>
<thead>
<tr>
<th>Correlation Factors</th>
<th>Pearson Co-efficient</th>
<th>F - Score</th>
<th>P  &lt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>BDI x Age</td>
<td>.10</td>
<td>0.30</td>
<td>0.60</td>
</tr>
<tr>
<td>BDI x Hb</td>
<td>.03</td>
<td>0.03</td>
<td>0.86</td>
</tr>
<tr>
<td>BDI x Urea</td>
<td>.11</td>
<td>0.37</td>
<td>0.55</td>
</tr>
<tr>
<td>BDI x Creatinine</td>
<td>.39</td>
<td>5.15</td>
<td>0.03</td>
</tr>
<tr>
<td>BDI x ESRD-SI</td>
<td>.29</td>
<td>2.51</td>
<td>0.12</td>
</tr>
<tr>
<td>BDI x PAS (C)</td>
<td>.14</td>
<td>0.57</td>
<td>0.46</td>
</tr>
<tr>
<td>BDI x PAS(B)</td>
<td>.32</td>
<td>1.9</td>
<td>0.19</td>
</tr>
<tr>
<td>BDI x BAI</td>
<td>.71</td>
<td>29.17</td>
<td>0.00</td>
</tr>
<tr>
<td>BDI x DAS (1-6)</td>
<td>.26</td>
<td>1.89</td>
<td>0.18</td>
</tr>
<tr>
<td><strong>BDI x MOS SF-36 Categories</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PF</td>
<td>.55</td>
<td>12.31</td>
<td>0.00</td>
</tr>
<tr>
<td>RP</td>
<td>.49</td>
<td>8.85</td>
<td>0.01</td>
</tr>
<tr>
<td>BP</td>
<td>.67</td>
<td>22.90</td>
<td>0.00</td>
</tr>
<tr>
<td>GH</td>
<td>.36</td>
<td>4.22</td>
<td>0.05</td>
</tr>
<tr>
<td>VT</td>
<td>.52</td>
<td>10.14</td>
<td>0.00</td>
</tr>
<tr>
<td>SF</td>
<td>.58</td>
<td>14.20</td>
<td>0.00</td>
</tr>
<tr>
<td>RE</td>
<td>.39</td>
<td>5.01</td>
<td>0.03</td>
</tr>
<tr>
<td><strong>MH</strong></td>
<td>.67</td>
<td>22.63</td>
<td>0.00</td>
</tr>
<tr>
<td>CDI x Age</td>
<td>.21</td>
<td>1.29</td>
<td>0.27</td>
</tr>
<tr>
<td>CDI x Months on dialysis</td>
<td>.12</td>
<td>0.38</td>
<td>0.54</td>
</tr>
<tr>
<td>CDI x Hb</td>
<td>.02</td>
<td>0.01</td>
<td>0.92</td>
</tr>
<tr>
<td>CDI x Urea</td>
<td>.24</td>
<td>1.65</td>
<td>0.21</td>
</tr>
<tr>
<td>CDI x Creatinine</td>
<td>.46</td>
<td>7.53</td>
<td>0.01</td>
</tr>
<tr>
<td>CDI x ESRD-SI</td>
<td>.18</td>
<td>0.98</td>
<td>0.33</td>
</tr>
<tr>
<td>CDI x PAS (C)</td>
<td>.11</td>
<td>0.33</td>
<td>0.58</td>
</tr>
<tr>
<td>CDI x PAS(B)</td>
<td>.37</td>
<td>2.74</td>
<td>0.12</td>
</tr>
<tr>
<td>CDI x BAI</td>
<td>.77</td>
<td>39.63</td>
<td>0.00</td>
</tr>
<tr>
<td>CDI x DAS (1-6)</td>
<td>.28</td>
<td>2.20</td>
<td>0.15</td>
</tr>
<tr>
<td>CDI x Total MOS SF-36 Score</td>
<td>.68</td>
<td>23.87</td>
<td>0.00</td>
</tr>
<tr>
<td>CDI x PF</td>
<td>.47</td>
<td>8.07</td>
<td>0.01</td>
</tr>
<tr>
<td>CDI x RP</td>
<td>.46</td>
<td>7.42</td>
<td>0.01</td>
</tr>
<tr>
<td>CDI x BP</td>
<td>.62</td>
<td>17.62</td>
<td>0.00</td>
</tr>
<tr>
<td>CDI x GH</td>
<td>.34</td>
<td>3.47</td>
<td>0.07</td>
</tr>
<tr>
<td>CDI x VT</td>
<td>.48</td>
<td>8.24</td>
<td>0.01</td>
</tr>
<tr>
<td>CDI x SF</td>
<td>.56</td>
<td>12.92</td>
<td>0.00</td>
</tr>
<tr>
<td>CDI x RE</td>
<td>.48</td>
<td>8.19</td>
<td>0.01</td>
</tr>
<tr>
<td>CDI x MH</td>
<td>.63</td>
<td>18.09</td>
<td>0.00</td>
</tr>
<tr>
<td>BAI x Months on dialysis</td>
<td>.26</td>
<td>1.97</td>
<td>0.17</td>
</tr>
<tr>
<td>BAI x Hb</td>
<td>.16</td>
<td>0.72</td>
<td>0.40</td>
</tr>
<tr>
<td>BAI x Urea</td>
<td>.12</td>
<td>0.40</td>
<td>0.53</td>
</tr>
<tr>
<td>BAI x Creatinine</td>
<td>.34</td>
<td>3.55</td>
<td>0.07</td>
</tr>
<tr>
<td>BAI x ESRD-SI</td>
<td>.22</td>
<td>1.42</td>
<td>0.24</td>
</tr>
<tr>
<td>BAI x PAS (C)</td>
<td>.04</td>
<td>0.05</td>
<td>0.83</td>
</tr>
<tr>
<td>BAI x PAS(B)</td>
<td>.45</td>
<td>4.34</td>
<td>0.05</td>
</tr>
<tr>
<td>BAI x DAS (1-6)</td>
<td>.28</td>
<td>2.16</td>
<td>0.15</td>
</tr>
<tr>
<td>BAI x Total MOS SF-36 Score</td>
<td>.62</td>
<td>17.79</td>
<td>0.00</td>
</tr>
<tr>
<td>BAI x MOSPF</td>
<td>.35</td>
<td>3.83</td>
<td>0.06</td>
</tr>
<tr>
<td>BAI x MOSRP</td>
<td>.42</td>
<td>6.13</td>
<td>0.02</td>
</tr>
<tr>
<td>BAI x MOSBP</td>
<td>.61</td>
<td>16.72</td>
<td>0.00</td>
</tr>
<tr>
<td>BAI x MOSGH</td>
<td>.30</td>
<td>2.87</td>
<td>0.10</td>
</tr>
<tr>
<td>BAI x MOSVT</td>
<td>.41</td>
<td>5.56</td>
<td>0.03</td>
</tr>
<tr>
<td>BAI x MOSSF</td>
<td>.53</td>
<td>11.20</td>
<td>0.00</td>
</tr>
<tr>
<td>BAI x MOSRE</td>
<td>.52</td>
<td>10.13</td>
<td>0.00</td>
</tr>
<tr>
<td>BAI x MOSMH</td>
<td>.62</td>
<td>17.73</td>
<td>0.00</td>
</tr>
<tr>
<td>DAS (1-6) x months on dialysis</td>
<td>.02</td>
<td>0.01</td>
<td>0.93</td>
</tr>
<tr>
<td>DAS (1-6) x DAS 7</td>
<td>.52</td>
<td>9.15</td>
<td>0.01</td>
</tr>
<tr>
<td>DAS (1-6) x DAS 8</td>
<td>.04</td>
<td>0.03</td>
<td>0.85</td>
</tr>
<tr>
<td>DAS (1-6) x DAS 9</td>
<td>.25</td>
<td>1.61</td>
<td>0.22</td>
</tr>
</tbody>
</table>
The Psychological Effects of Dialysis on the Patient and their Partner
Appendix J - Correlation Results

<table>
<thead>
<tr>
<th>MOS SF-36 Categories</th>
<th>PF</th>
<th>RP</th>
<th>BP</th>
<th>GH</th>
<th>VT</th>
<th>SF</th>
<th>RE</th>
<th>MH</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>.08</td>
<td>.01</td>
<td>.22</td>
<td>.07</td>
<td>.03</td>
<td>.39</td>
<td>.18</td>
<td>.27</td>
</tr>
<tr>
<td></td>
<td>0.17</td>
<td>0.00</td>
<td>1.31</td>
<td>0.12</td>
<td>0.02</td>
<td>4.18</td>
<td>0.81</td>
<td>1.93</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PAS (B) x PAS (C)</td>
<td>.51</td>
<td>6.11</td>
<td>0.02</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PAS (B) x MOS/SF</td>
<td>.23</td>
<td>0.94</td>
<td>0.35</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PAS (B) x MOS/MH</td>
<td>.48</td>
<td>5.08</td>
<td>0.04</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PAS (B) x months on dialysis</td>
<td>.14</td>
<td>0.25</td>
<td>0.62</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PAS (C) x months on dialysis</td>
<td>.16</td>
<td>0.49</td>
<td>0.5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table K.2
CORRELATION BETWEEN ASSESSMENT INSTRUMENTS FOR THE PARTNER SUBJECT GROUP (n = 22)

<table>
<thead>
<tr>
<th>Correlation Factors</th>
<th>Pearson Co-efficient</th>
<th>F Score</th>
<th>P &lt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>SBDI x Age.s</td>
<td>.21</td>
<td>0.87</td>
<td>0.36</td>
</tr>
<tr>
<td>SBDI x SBAI</td>
<td>.53</td>
<td>7.19</td>
<td>0.02</td>
</tr>
<tr>
<td>SBDI x SDAS (1-6)</td>
<td>.41</td>
<td>3.34</td>
<td>0.09</td>
</tr>
<tr>
<td>SBDI x months on dialysis</td>
<td>.09</td>
<td>0.15</td>
<td>0.70</td>
</tr>
<tr>
<td>SBDI x ESRDSI</td>
<td>.05</td>
<td>0.05</td>
<td>0.82</td>
</tr>
<tr>
<td>DAS (1-6) x MOS SF-36 Categories</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>PF</td>
<td>.12</td>
<td>0.27</td>
</tr>
<tr>
<td></td>
<td>RP</td>
<td>.17</td>
<td>0.54</td>
</tr>
<tr>
<td></td>
<td>BP</td>
<td>.26</td>
<td>1.3</td>
</tr>
<tr>
<td></td>
<td>GH</td>
<td>.47</td>
<td>5.00</td>
</tr>
<tr>
<td></td>
<td>VT</td>
<td>.45</td>
<td>4.67</td>
</tr>
<tr>
<td></td>
<td>SF</td>
<td>.23</td>
<td>1.01</td>
</tr>
<tr>
<td></td>
<td>RE</td>
<td>.52</td>
<td>6.75</td>
</tr>
<tr>
<td></td>
<td>MH</td>
<td>.55</td>
<td>7.89</td>
</tr>
<tr>
<td>SDAS x SBAI</td>
<td>.32</td>
<td>2.09</td>
<td>0.17</td>
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### Table K.3
CORRELATION BETWEEN ASSESSMENT INSTRUMENTS FOR THE PATIENT AND PARTNER GROUP

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