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An Investigation of the Validity and Reliability of the Severity of Renal Disease Scale (SORDS)

A Dissertation Submitted to the College of Graduate Studies and Research in Partial Fulfillment of the Requirements for the Degree of Doctor of Philosophy in the Department of Psychology University of Saskatchewan Saskatoon

By
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Spring, 2001

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Abstract

Physical illness severity is known to both moderate and suppress relationships amongst psychological variables in health psychology research. The Severity of Renal Disease Scale (SORDS) was developed to provide a single score reflecting disease severity of renal patients independent of confounding psychosocial influences. This study examined SORDS’ reliability and validity and its relevance as a research tool assessing the psychological effect of illness severity.

Data was collected from 127 renal patients (predialysis, haemodialysis and continuous ambulatory peritoneal dialysis). SORDS was compared with the Endstage Renal Disease Severity Index (ESRD-SI; Craven et al. 1991), the SF-36 (Ware, 1992), the Beck Depression Inventory - 2nd Edition (BDI-II) (Beck, 1996) and a subset of BDI-II items reflecting cognitive features only (BDI-CS) at differing stages of renal disease and time on dialysis. A subset of CAPD patients (n = 22) was used to assess the inter-rater reliability of SORDS and ESRD-SI.

SORDS inter-rater reliability estimates were low suggesting that the use of SORDS with medical chart data at this time is problematic. SORDS should be used only by medical practitioners who are aware of patients’ standing on SORDS variables. There was however strong support for SORDS’ validity.
SORDS and the ESRD-SI correlated highly, but SORDS was better able to discriminate among patients from different treatment groups. SORDS and ESRD-SI scores were marginally related to increasing disease severity and patients’ self-perceptions of health as measured by the SF-36. SORDS and the ESRD-SI were unrelated to time on dialysis, age, BDI-II depression scores and general health status as measured by the SF-36.

The utility of SORDS as a moderator variable measure in psychosocial research with renal patients was demonstrated. Severity of renal disease was shown to have differential impact on measured levels of depression for HD versus CAPD patients. CAPD patients were significantly more depressed than patients receiving in-hospital HD at the lowest severity level on SORDS. This finding was independent of dialysis duration or age.

It was concluded that SORDS is a valid index of renal disease severity and that illness severity as assessed by SORDS has an important role as a moderator variable in psychosocial research with renal patients. Understanding of a renal patient’s adjustment to disease and its treatment is enhanced by knowledge of both that patient’s physiological status and how that patient has adjusted to that status. These results have important implications for treatment assignment and psychosocial assessment and intervention of renal patients and their families.
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1. Introduction

An increasing number of patients present every year with progressive renal insufficiency. Recent prospective studies in Britain suggest that approximately 80 patients per million of the population under 80 years of age develop end-stage renal failure, or disease (ESRD) which requires ongoing treatment (Nahas et al., 1993). The equivalent rate in the United States currently exceeds 120 patients per million (Nahas et al., 1993). The incidence and prevalence of ESRD have also increased greatly in Canada over the last 2 decades (Hutchinson, 1999).

The treatment of endstage renal disease is a dramatic technical success. Before the invention of dialysis treatment in the 1940s, the average survival of patients with renal failure was approximately 2 weeks (Hutchinson, 1999). With the current use of haemodialysis, peritoneal dialysis and transplantation, average survival is now approximately 5 years. Ironically, prolonging the survival of patients with kidney failure, the prevalence of endstage renal disease will continue to rise well into the next century (Hutchinson, 1999). This trend has considerable medical, social, and economic consequences because of the high cost of renal replacement therapy, the associated high mortality and the effect on patients' quality of life (Nahas et al., 1993).
In the United States it costs an estimated US$47, 400.00 to support one renal patient for one year. The costs in Canada are estimated to be similar (Hutchinson, 1999). Health care budgets will have to absorb the increasing costs that come with the success of treatment and should plan proactively. Otherwise, timely, adequate distribution of resources may not occur until the system is in crisis and health care workers are burnt out trying to cope with increased demands using resources designed for a smaller system (Hutchinson, 1999). This leads to deterioration in both the well-being of health care workers and in the quality of their work.

As such, predicting numbers of patients who will require dialysis and transplantation is of considerable interest to health care planners in order to accurately forecast equipment, facility and other resource requirements. Of particular concern in this respect is the unexplained high variability noted in the literature in the utilization of hospital resources to provide patient care among countries, regions, hospitals and physicians.

The explanations for variations are numerous, and include differences in the severity of illnesses treated in different medical centres, the additional costs incurred by providing programs in medical education, and differences in medical practice and expertise. Although the characteristics of all the variable factors influencing variations in care and resource consumption remain elusive and under study, the pressure to reduce health care costs has produced a demand for standardization of care and associated costs resulting in fears by physicians and renal patients alike that quality and availability of care may be
sacrificed. At the same time, data from the American ESRD program suggests that the death rate on haemodialysis (HD) is significantly higher in the US than other industrialized countries, where mortality rates continue to decline despite adding older and presumably sicker patients. Alarmingly, the U.S. rate continues to increase out of proportion to any change in patient mix (Hull, 1992), and is accompanied by allegations that reductions in reimbursement by almost two thirds have forced nephrologists to resort to unsafe, short dialysis, and dialyzer reuse (Friedman, 1994). These practices have been cited as factors explaining the differences in survival data between the US and other countries.

The pressure to reduce health care costs and improve standardization of care requires prospective stratification of patient populations and accurate prediction of resource utilization, hospital charges, and distribution of hospital personnel. The question remains whether existing methods of care assessment meet the requirements of this demand when inadequate identification and control of potentially confounding variables are characteristic of the entire nephrology research literature. Of particular concern is the use of health status instruments characterized by the presence of confounding variables in studies measuring treatment effectiveness and outcome. These confounding variables, not measurable by psychological tests, and involving effects not identified, quantified or controlled, are often present in studies being used to justify budget cuts and expenditure in health care resource planning. Some examples of potential confounding variables are age, marital status,
employment, race, length of time on treatment, duration of illness and illness severity.

Severity of illness in particular has been identified as an important variable that may greatly influence factors related to treatment outcome, mortality and quality of life. It is likely that the effect of illness severity may inflate the error in the data, thus obscuring true effects. Although the error may in fact be systematic variance in the data due to severity of illness, this variable has seldom been measured accurately. Its absence in many studies may explain the conflicting findings. For example, when severity of illness is included in analyses, it has been shown that there is a significant amount of variability in disease severity between institutions indicating that the experience of one institution may not be applicable to another. This is especially pertinent to the results of therapeutic trials in which outcome is assessed in terms of mortality rates. It may also apply to the lengths of stay and cost of intensive care thus addressing issues of variable resource consumption among hospitals (Pollack et al., 1987).

In other studies, results suggest that the lack of illness severity data detracted considerably from the accuracy of mortality predictions. As a result, the quality of care status of hospitals with a disproportionate share of severely ill patients was negatively biased (Green et al., 1990). These investigators advised that consumers and health regulators be cautious about interpreting high mortality status as an indication of deficiencies in the quality of care. High mortality status may reflect a mix of more severely ill patients, and may not
content valid, and was a reliable indicator of progressive severity of renal disease, but this research was not published.

The research conducted for this dissertation seeks to build upon that which was carried out with SORDS in the 1980's. Specifically, using current samples of renal patients, the reliability and validity of SORDS was investigated. The investigations also examined the potential utility of SORDS being used as either a suppressor variable measure, or as a moderator variable in psychosocial research with renal populations.
2. Review of the Literature

The following section of this document does not exhaustively review chronic renal failure and endstage renal disease. Instead, the intent is to selectively review the literature to underscore how illness severity, when not adequately controlled for in data collection and analyses, leads to mixed, and often confusing results. Such a review will demonstrate the need for a measure of illness severity independent of psychosocial influences, and hence, lead to a discussion of the suitability of the Severity of Renal Disease Scale (SORDS) for this purpose.

An overview of renal failure and its treatment will be followed by a review of the nephrology and health psychology literature as it pertains to measurement of disease severity in psychosocial research with renal patients. The order of presentation is intended to lay a foundation for the introduction of SORDS as an improved alternative measuring disease severity. As such, SORDS will not be discussed until near the end of the literature review.

2.1 CRF and ESRD: An Overview

2.1.1 CRF and ESRD: Definitions and Descriptions

Chronic renal failure (CRF) is the result of several pathophysiological processes causing irreversible damage to kidney tissue (Smith et al., 1985; Smith, 1997). It is a gradual and progressive loss of the ability of the kidneys to
excrete wastes, concentrate urine, and conserve electrolytes because of massive destruction of nephrons (Smith et al., 1985). The failure is slowly progressive, and may take place over a course of up to 20 years (Smith et al., 1985; Smith, 1997). The constellation of signs and symptoms that occur with chronic renal failure is referred to as uremia, or the uremic syndrome (Lancaster, 1984). The symptoms are related to the fluid and electrolyte abnormalities, and disordered regulatory functions (e.g., anaemia, hypertension, and accumulation of uremic toxins) which cause physiologic changes and alter the function of various organ systems (Schaubel et al., 1999). Ultimately, the progression of CRF may continue to endstage renal disease, and death. The aim of management of chronic renal failure is to delay the progression towards end-stage renal failure and dialysis (Storset et al., 1995). The focus of much of the nephrology literature is limited to ESRD, although data on CRF, as a long-term progressive condition, is both plentiful and available (Sensky, 1993).

The terms chronic renal failure (CRF) and endstage renal disease (ESRD) appear to be used interchangeably in many of the published works that refer to both. Steadman's Medical Dictionary (1990) distinguishes between the two by level of severity or disease progression. ESRD, though also a progressive, and potentially long-term condition, is distinguished from CRF by many researchers at the point that dialysis is indicated (Cummings, 1970; Steele et al., 1976; Bonney et al., 1978; Czaczkes & Kaplan De-Nour 1978; Smith et al., 1983; Craven et al., 1991; Sensky, 1993; Sensky, 1996). For
example, it has been defined as “that stage of renal function in which the
kidney is no longer able to maintain the integrity of the internal environment of
the organism” (Papper, 1971). Others are more specific, defining ESRD as the
stage at which a person has 10 per cent, or less, of normal renal function
remaining (Gabriel, 1990). Generally, it is believed that once chronic renal
failure has advanced to a certain point, it usually progresses to end-stage renal
failure. However, there does not appear to be a universally agreed upon point
at which progression becomes inevitable (Williams, 1993). Rather, this point
seems to vary with both the disease and the individual (Williams, 1993). For the
purposes of this research, endstage renal disease (ESRD) is defined as
irreversible kidney disease causing chronic physiological abnormalities and
necessitating treatment with dialysis or kidney transplantation for survival. In
other words, in ESRD, the maintenance of life can only be ensured by dialysis
or renal transplantation.

2.1.2 Causes of CRF/ESRD

There are many different underlying causes of chronic renal failure, and
its onset can be relatively short term or it can last for years (Koch & Muthny,
1990). Among the most frequent causes are autoimmune and inflammatory
processes of the kidney (especially glomerulonephritis and pyelonephritis).
Other common causes are renal cystic diseases (partly hereditary), vascular
lesions of the kidney as sequelae of a diabetes mellitus, continuance of an
acute renal insufficiency and renal damage due to continued abuse of
analgesics (phenacetin kidney) (Koch & Muthny 1990), and a variety of renal
tubular disorders which prevent the excretion of acid resulting in a systemic metabolic acidosis (Koch & Muthny 1990).

Glomerulonephritis, often referred to as 'nephritis', is a bilateral, diffuse disease of the kidneys (Smith et al., 1985; Smith, 1997), and accounts for almost half the patients who require dialysis treatment (Gabriel, 1990). The disease is caused by persistent inflammation of the nephrons of the kidney (Koch & Muthny, 1990). The inflammation leads to damage and scarring so that the nephrons wither away, and proteins from the blood leak into the urine. The nephrons are the primary filtering units of the kidneys and if the inflammation is widespread many nephrons are lost and the kidneys become unable to filter sufficient water and waste products. It is often asymptomatic, and is considered to be irreversible (Gabriel, 1990).

Urinary tract infections are among the most common of all bacterial infections, and a leading cause of CRF/ESRD (Smith et al., 1985; Smith, 1997). Cystitis is the inflammation of the urinary bladder and occurs most frequently in females (Smith, 1997). Acute pyelonephritis is a bacterial infection of kidney tissue with the infection beginning in the lower urinary tract and ascending to the kidneys (Smith, 1997). It temporarily affects renal function, but the process of developing CRF/ESRD occurs over many years, or after several extensive and severe infections (Gabriel, 1990). Chronic pyelonephritis is the result of repeated infections producing inflammation and widespread destruction of nephrons, and replacement with scar tissue (Smith, 1997). With inflammation, scars develop which gradually distort and destroy the kidney substance, and
this continued destruction of the kidney leads to chronic renal failure and ESRD (Gabriel, 1990).

Diabetes mellitus is characterized initially by increased renal size and an increase in renal plasma flow and glomerular filtration rate (GFR) (Brunskill & Klahr 1993). Some diabetic patients develop a nephropathy which progresses to renal failure, but it is not clear how or why this occurs. According to some, apart from the raised levels of blood sugar and fats that accompany diabetes, damage occurs to small blood vessels in all parts of the body (Gabriel, 1990). Kidneys contain many such blood vessels, and if they are sufficiently damaged, blood vessels supplying nephrons become blocked. The nephron fades, and is replaced with scar tissue, a condition known as diabetic nephropathy. It is estimated that 25% of patients receiving dialysis have diabetic renal failure (Gabriel, 1990).

In insulin-dependent diabetes (IDDM), about 30 per cent of patients develop nephropathy over a 20- to 30-year period, but the relationship between early or sustained hyperfiltration and the later irreversible nephropathy has not yet been confirmed unequivocally. Although less information is available in non-insulin-dependent diabetes (NIDDM), it appears the long-term risk of developing diabetic nephropathy is similar (Brunskill & Klahr 1993).

Diabetic nephropathy is rarely seen until at least 5 years after the diagnosis of IDDM (Andersen et al., 1983). It has been shown that those patients particularly at risk of renal involvement have a urinary albumin excretion which is well above normal but not detectable on routine dip-stick
testing. These patients not only have a higher risk of nephropathy but also a significant increase in cardiovascular mortality (Williams, 1993). Renal function inevitably deteriorates in established diabetic nephropathy. Treatment with antihypertensives or dietary protein restriction may slow progression, but does not halt it (Williams, 1993).

In NIDDM, other factors may be more important, particularly in the older patient (Ritz et al., 1991). Ritz and his colleagues (1991) have pointed out that ischemic nephropathy due to large-vessel disease is an under diagnosed cause of renal failure in some diabetics and should be suspected when worsening of renal function is not accompanied by heavy proteinuria.

If there is persistent obstruction to urine flow, pressure develops between the obstruction and the kidney. The kidneys cannot produce urine continually under pressure and will eventually begin to fail. There are three common causes of this kind of renal failure: (1) enlarged prostate gland; (2) kidney stones; and (3) poorly functioning urethral valves that restrict urinary flow. This results in back pressure that is transmitted to the bladder, ureter and kidneys (Smith, 1997).

Chronic renal failure can also be caused by reflux nephropathy, a congenital anatomical abnormality. In this condition, sphincter incontinence occurs at the junction of the ureter with the bladder, allowing the reflux of urine back up the ureter and into the kidney. Infection usually develops, and the inflammation and formation of scar tissue leads to chronic renal failure (Smith, 1997).
2.1.3 Concomitant Diseases

End-stage renal disease is a serious condition that is complicated by the presence of a variety of comorbid conditions, many of which themselves can be life-threatening. Although the kidney can maintain homeostasis despite 70-80% loss of function (Smith, 1997), when overall renal function is less than 20-25% of normal, various pathophysiologic changes take place. These are briefly outlined below (Smith, 1997).

Uremic manifestations in the skin present very distressing symptoms for the renal patient (Smith, 1997). Pruritus, a relentless itching of the skin, and attendant scratching predispose the patient to infection while making him or her irritable, restless, and frustrated. Uremic skin is often deeply pigmented with a yellowish cast. Treatment is symptomatic (Smith, 1997).

The most common cardiovascular problem in CRF/ESRD is hypertension, which has two basic causes: (1) fluid and sodium overload; and (2) malfunction of the renin-angiotensin system. Sodium and water retention causes circulatory overload and elevated blood pressure. In renal failure, the kidneys apparently do not recognize the rise in blood pressure and may continue to produce large quantities of renin, which is converted to angiotensin, which causes an increase in blood pressure. Cardiovascular problems related to renal failure may also include hypertensive heart disease, hyperkalemia (grossly elevated serum potassium levels), myocardial calcification, pericarditis (inflammation of the pericardial sac due to uremic toxins or viral infection, causing friction of the pericardium layers), and arterial calcification (Gabriel, 1990).
Effects of chronic renal failure and ESRD on the hematological system include anemia, a defect in the quality of platelet, an increased bleeding tendency, and a change in the physiology of red and white cells. Causes of anemia include: (1) decreased red blood cell production caused by the diseased kidney; (2) decreased survival time of red blood cells due to elevated uremic toxins; and (3) loss of blood through gastrointestinal bleeding. Chronic HD patients are most at risk of anemia because of dialysis-related problems: (1) dialysance of iron and vitamins; (2) introduction of copper, oxidants, or excessive heat into the hemodialysate; and (3) blood loss (leaks through rents in the dialyzer membrane, frequent venipuncture for tests). Patients with CRF/ESRD also have a defect in the quality of platelet resulting in prolonged bleeding time, decreased platelet adheriveness, and abnormal prothrombin consumption (Smith, 1997).

Pulmonary problems in CRF/ESRD include pulmonary edema, pleuritic pain, pleuritic rub, uremic pleuritis, and uremic pneumonitis (a manifestation of fluid overload). The symptoms are depressed cough reflex, increased susceptibility to infections, and an increased respiratory rate (Smith, 1997).

The entire gastrointestinal system is affected by uremia. Patients often suffer from fetor uremicus, the smell of urine and ammonia on the breath caused by conversion of excessive salivary urea into ammonia. The ammonia also causes gum ulceration and bleeding. Esophagitis, gastritis, duodenal ulcers, nausea, vomiting, diarrhea, anorexia, and lesions of the small and large bowel are also common, and are caused by elevated serum uremic toxins that
cause inflammation and ulceration of the gastrointestinal mucosa. Malnutrition is usually present, and presents an immediate treatment concern (Smith, 1997).

Metabolic consequences of CRF/ESRD are numerous. The most common problems are those of carbohydrate intolerance, hyperlipidemia, and protein metabolism (Gabriel, 1990). Carbohydrate (glucose) intolerance is caused by resistance of peripheral tissues to insulin, delayed insulin production by the pancreas, and increased half-life of insulin (Nahas et al., 1993). Because of decrease in renal function, the end products of protein metabolism accumulate, as reflected by an increase in blood urea nitrogen (BUN). An elevated BUN is partly responsible for the development of the uremic syndrome (Smith et al., 1985; Williams, 1993). As renal dysfunction worsens, the elimination of many drugs and their metabolites also decreases, and may cause higher blood and tissue concentrations of both drugs and metabolites and toxicity, even with typical dosages. It has been estimated that one-third of all neurological symptoms in a uremic population are caused by drug toxicity. For example, penicillin and cephalosporins in excessive dosage can cause myoclonic jerks and grand mal seizures, while excessive sedation and/or psychiatric symptoms are seen with many sedatives, hypnotics, and tranquilizers (Smith, 1997).

A variety of endocrine problems are also present in CRF/ESRD. Pituitary function is affected in that even though there is an elevation of serum growth hormone, there is failure to respond to the growth hormone (Smith et al., 1983). This has been demonstrated in studies with children with CRF (Bailey, 1972).
When renal failure is advanced, infertility takes place in men and women. Amenorrhea and cessation of ovulation take place in women, and there is decreased libido in both sexes. Haemodialysis improves this situation, but conception and successful pregnancy are very rare (Smith, 1983).

Nervous system changes occur in virtually all uremic patients. The signs and symptoms are numerous and vary according to the degree of uremia and the part of the nervous system affected - central, peripheral, or autonomic (Williams, 1993). Changes may occur in mental function, muscle function, behavior, and sensory and motor nerves (Smith et al., 1983).

Changes in mentation include shortened memory and attention span, confusion, stupor, coma, and convulsions. Depending upon the patient's premorbid personality, behavior changes may range from slight irritability to complete withdrawal. Other changes include psychosis, delusions, agitation, and depression. Treatment for renal disease is itself associated with neuropsychological deficits of both acute and chronic courses. Uremic encephalopathy presents as a typical acute brain syndrome, which is usually alleviated by dialysis, and relieved by transplantation (Sensky, 1989). Patients on dialysis may also develop a chronic brain syndrome known as progressive dialysis encephalopathy, or dialysis dementia, which is sometimes associated with aluminum toxicity, but not always. It is characterized by speech disturbances, cognitive impairment, and behavioral changes. It is irreversible, although early symptoms may be controlled by benzodiazepine medication. Symptom onset usually occurs after at least 2 years of treatment, and the
syndrome nearly always progresses to coma and death, with few patients surviving beyond nine months (Burnett et al., 1986). Early symptoms include change in personality and cognitive functioning, and agitation, hostility, paranoia, depression or flat affect. Diminished interest and spontaneity are often reported (Hart & Kreutzer 1988). Disorientation, impaired judgment, confusion, memory problems, and decreased attention have also been noted by staff (Hart & Kreutzer, 1988). Apart from the more serious organic brain syndromes, changes in cognitive functioning and mood, as evidenced by changes in mental alertness and efficiency in relation to time after dialysis have often been reported, indicating some short term changes in toxic uremic status between dialysis sessions (Hart & Kreutzer, 1988).

Uremic encephalopathy is seen in patients who are late in reaching treatment. Clinical manifestations include virtually every neuropsychiatric sign and symptom. Untreated, uremic encephalopathy may result in delirium, focal neurological signs, coma, and death (Hart & Kreutzer, 1988).

Changes in muscles function and sensory and motor nerves are also observed. Slowing of peripheral nerve conduction leads to peripheral neuropathy manifested by symmetrical numbness and burning, beginning in the toes, and spreading up the legs, foot drop and a “burning feet” syndrome, known as peripheral neuropathies (Smith et al., 1983).

Lancaster (1972) remarks that every patient with CRF/ESRD will develop imbalances in the interrelationship among calcium, phosphate, vitamin D,
parathyroid glands, bones, and kidneys. Adequate amounts of protein, calcium, and phosphate must be available for normal bone structure. Parathyroid hormone is important in calcium and phosphate metabolism. Since the kidney is the primary means of phosphate excretion, the decreased glomerular filtration rate (GRF) in renal failure causes retention of phosphate and an increased plasma phosphate (Guyton, 1976). An elevation in the plasma phosphate upsets the normal calcium phosphate ratio, and to compensate, the ionized plasma calcium decreases (Guyton, 1976). Because the kidneys are unable to convert vitamin D to an important active metabolite, there is decreased absorption of calcium from the intestines which worsens the hypocalcemia (Guyton, 1976). When the calcium phosphate product exceeds a certain limit, calcium phosphate crystals form. Because they are insoluble, these crystals precipitate in various parts of the body (metastatic calcifications), such as the brain, eyes, gums, joints, lungs, myocardium, blood vessels, and skin. A secondary hyperparathyroidism develops and is one of the factors causing dissolution of the bones. In advanced renal failure, extreme bone disturbances often develop that dominate the course of illness (Guyton, 1976).

CRF/ESRD is a condition that manifests itself in many concomitant diseases and disorders. Patients with CRF/ESRD who have but few of these conditions are relatively speaking, not too ill beyond the obvious reduction or loss of kidney function. Other patients, on the other hand, can become critically ill even while treated for kidney disease. Thus, the potential range of illness severity in these patients is enormous.
2.1.4 Treatment Modalities for ESRD

There are two forms of treatment for endstage renal disease: dialysis and kidney transplantation. No patient is indefinitely committed to either form of treatment. However, any patient who wishes to have a transplant will require dialysis to keep him or her alive until a suitable kidney becomes available. If, at some time after transplantation, the new kidney fails, the patient then returns to HD or to continuous ambulatory peritoneal dialysis (CAPD). Different treatments are used at different times, taking into account the wishes and requirements of the individual (Lowrie et al., 1994).

2.1.4.1 Dialysis: Haemodialysis and Peritoneal Dialysis

End-stage renal disease is a complex medical phenomenon. It has been said that its treatment alone includes features which make this condition unique among chronic physical illnesses (Sensky, 1993). Currently, haemodialysis is the most common treatment for uremia and ESRD. In many cases, haemodialysis generally occurs two to three times weekly, thereby placing the patient in a position completely dependent upon a machine for survival. This dependence extends to renal unit staff, or to family members where patients dialyze at home. In some cases, home dialysis is only possible because of the active help of family members in which case the dialysis procedures become part of the family routine. Between sessions, patients often show no signs of the illness. As a result, renal unit staff and family alike may put pressure on the individual to lead a ‘normal’ life, placing him or her into a form of double bind (Alexander, 1976).
When the glomerular filtration rate falls below 5% of normal in adults with chronic renal failure, chronic health problems will be experienced which can be treated conservatively until dialysis is required. For some patients, haemodialysis is not a long-term treatment option. Patients with diabetes may develop diabetic nephropathy as a peripheral vascular disease, and neuropathy, both of which may make the creation and maintenance of vascular access very difficult (Smith, 1997). Another complication of diabetes is cardiac disease, and may also contraindicate haemodialysis because it may place the patient at risk of cardiovascular instability and haemodialysis intolerance (Koch & Muthny, 1990).

In haemodialysis treatment, blood is taken by means of an arteriovenous fistula, a shunt placed at the patient's arm. The blood is then mechanically drawn to a dialyzer with an artificial selective permeable membrane (Koch & Muthny, 1990). Through diffusion with a dialysis solution, substances usually eliminated with the urine are extracted from the blood, and the electrolyte balance is restored. The 'purified' blood then is fed back to the body through the shunt (Smith, 1997).

There are different possible settings for the haemodialysis session (Hom et al., 1991) The sessions take place 3 times per week with each session lasting 4 to 5 hours. The session can take place in the dialysis center either with the hospital staff in charge (in-center dialysis), involving suitable patients trained to a certain degree in the procedure (limited care dialysis), or it can take
place in the patient's home after training of the patient and his/her partner (home dialysis) (Koch & Muthny, 1990).

With peritoneal dialysis (PD), the peritoneum serves as a membrane (Smith, 1997). By use of a permanent catheter, a dialysis solution is infused into the peritoneal cavity, where it stays for a certain period of time extracting substances usually eliminated with the urine through diffusion across the peritoneal vascular network restoring the electrolyte balance (continuous ambulatory peritoneal dialysis, or CAPD) (Schwenk & Halstenson, 1989; Shulman et al., 1990). CAPD is usually the treatment of choice for patients with diabetic nephropathy. Being continuous, the treatment is ideal for those patients who are haemodynamically unstable or have few sites suitable for vascular access (Smith, 1997).

The majority of patients on haemodialysis are anemic, and this is felt to be an important factor contributing to the decreased quality of life experienced by these patients (Laupacis et al., 1991). Recombinant human erythropoietin is effective in correcting the anemia of endstage renal disease (Shulman et al., 1990).

2.1.4.2 Transplantation

Transplantation, or grafting, is the operation of putting a kidney obtained from another person into a patient. Donor kidneys are of two types, live and cadaver. A live donor kidney is usually obtained from a relative of the patient. A cadaver kidney from a deceased donor with largely identical tissue, like the live
kidney, takes over the renal function following the transplantation procedure. Cadaver kidneys are the most frequently used (Lowrie et al., 1994).

Normally, the body cannot accept tissues from a different individual except in the special case of identical twins (Gabriel, 1990). Rejection is the process by which the body destroys transplanted organs. The prevention of transplant rejection is accomplished by long-lasting immunosuppressive drugs (Friedman, 1994).

There are a number of advantages and disadvantages to kidney transplant. The greatest advantage of a successful transplant is freedom from repeated dialyses. There are no dietary or fluid restrictions, and for women, childbearing is again possible. Anaemia and related tiredness disappear, and it may be possible to return to employment. Although evidence regarding improvement in quality of life is not unequivocal (Evans et al., 1985; Devins, 1989; Sensky, 1989), many of the troublesome aspects of HD seem to be ameliorated.

Among the disadvantages of transplantation are the physical and emotional hardships of receiving major surgery without guarantee that the transplant will be successful. There may be operations required in order to prepare for the transplant surgery, such as the removal of the diseased kidneys or surgery to the bladder. Some kidneys, even if initially successful, eventually lose their function, and the patient returns to dialysis. The transplant patient will need to take daily medication to prevent rejection for as long as the grafts lasts (Sensky, 1989).
2.1.5 Mortality

Many factors affect mortality rates among ESRD patients on dialysis, including age, sex, race, renal diagnosis, and diabetic nephropathy (Eggers, 1990; Lowrie et al., 1994). Non-compliance with diet restrictions has been estimated to account for 4% of the deaths of dialysis patients (Held, 1987). Although a combination of nutritional status (e.g., percent of ideal weight) and dialysis intensity appear to contribute most to risk of death, studies supporting these findings suggest that these variables explain only 20% or less of the death risk differences among patients (Lowrie et al., 1994). Therefore, focusing solely on dialysis intensity, and nutritional status of patients, as well as other predictors of mortality may cause investigators and clinicians to overlook unmeasured, systematic sources of variance, such as disease severity.

The most important characteristic influencing mortality among ESRD patients on HD is the change in age and diagnostic distribution (Keane & Collins, 1994). Both age and presence of diabetic nephropathy are increasing among newly treated patients, both in the United States and Europe (Held et al., 1987). The average age of dialysis patients has increased by over 5 years during the past decade, which may in part be explained by clinics accepting a greater number of older patients who would have previously been denied treatment due to a lack of treatment facility resources (Eggers, 1990). Studies indicate that survival decreases rapidly with advancing age at time of renal failure, from 95.1% among non-diabetic patients 15 to 24 years to 52.5% for patients over the age of 85 (Eggers, 1990). Although there is no direct evidence
of increased severity of disease among this category of patients, the extension of dialysis therapy to older patients is suggestive that additional, unmeasured changes in severity may account for these mortality changes.

Despite the life-saving benefits of HD, mortality is still high among ESRD patients. During the past decade, the gross mortality rate of patients undergoing maintenance dialytic therapy has progressively increased in the United States to a figure approaching 24% (Keane & Collins, 1994). This figure is more than twice the mortality figures in Europe, Australia, and Japan (Held et al., 1987; Keane & Collins, 1994). It may be that the US has a very high acceptance rate for renal replacement therapy (RRT), and is treating patients with more serious comorbid conditions than a country with a low acceptance rate (Held et al., 1987; Keane & Collins, 1994), thus resulting in higher mortality rates. While some argue that the data may indeed reflect a case mix of varying degrees of disease severity among patient groups, other evidence suggests that mortality rates continues to increase out of proportion to any change in patient mix (Hull, 1992).

Without clear measures of severity of illness, conclusions about case mix and mortality remain unclear and have resulted in serious indictments against the health care system. For example, researchers have expressed the fear that the pressure to reduce health care costs has produced a demand for standardization of care and associated costs that has resulted in lowered standards for quality and availability of care (Friedman, 1994). Specifically, the rising death rate has been attributed by some to a drastic reduction in American
federal reimbursement for dialysis care and an attendant decrease in quality of care. In 1991, the reimbursement decreased to almost one third of payment in 1974, a reduction which forced nephrologists to resort to two harmful practices: (1) unsafe, short dialysis, and (2) dialyzer reuse (Friedman, 1994). These practices have been cited as factors explaining the differences in survival data between the US and other countries. Still others argue that these practices affect mortality rates in only the severely ill (Eggers, 1990).

Depression has also been associated in the literature with diminished survival of patients treated with HD for ESRD. However, the long term effects of depression on the course of ESRD are largely unknown, and estimates of the frequency of depression in ESRD patients vary from five to one hundred percent (Petersen et al., 1991). Diagnostic and prognostic difficulties appear to be related to inadequate control over the effect of illness severity (Petersen et al., 1991). Findings of increased mortality among the depressed may indicate that the more severely ill patients are more likely to be depressed, however, this conclusion requires further investigation utilizing measures of physiological severity independent of psychosocial influences as well as measures of depression that are not confounded by somatic symptoms.

Measures of disease independent of psychosocial and other non-disease factors are clearly needed to clarify the correlates of mortality in this complex population. In the following sections, diverse aspects of ESRD research will be reviewed in order to demonstrate, in each case, the inherent difficulties created by the lack of adequate disease severity measures.
2.2 Psychonephrology: Psychosocial Factors Associated with ESRD

With increasing technological sophistication, the focus of renal replacement therapy has turned from life-support procedures to life-enhancing techniques (Sensky, 1993). In accord with this, clinicians and researchers have attempted to document and understand the numerous psychosocial ramifications of chronic HD in the treatment of endstage renal disease (Kutner et al., 1985; Craven et al., 1987; Hinrichsen et al., 1989; Petrie 1989; Petersen et al., 1991), and the impact of these ramifications on morbidity and mortality (Foster & Cohn, 1973; Farmer et al., 1979; Wai et al., 1981; Shulman et al., 1990). Comparisons of psychosocial factors between different forms of treatment for ESRD dominate the literature (Sensky, 1993), but because of the many psychological and physiological implications and reactions to machine-dependent life, chronic haemodialysis, in particular, has been of interest to practitioners and researchers in the behavioral sciences (Kaplan De-Nour & Czaczkes, 1976). This interest is reflected in the preponderance of studies focusing on HD patients. Because of the complex, dynamic nature of renal disease many factors confound assessment and treatment of renal patients, thus making outcome studies in this area highly susceptible to unmeasured, and therefore uncontrolled, sources of error.

2.2.1 Neuropsychological Issues in Renal Disease

Uremia is associated with a wide variety of neurobehavioral abnormalities that vary in intensity and number depending of the extent of renal
failure (Wolcott et al., 1988), and can exert a significant impact on psychological test results (Yanagida & Strelzer, 1979).

Previous studies of cognitive function in chronic HD patients have demonstrated impaired performance on measures of short and long term visual, auditory, and verbal memory, attention and concentration, sequential information processing, and IQ test score patterns, indicating cortical dysfunction (Hart & Kreutzer, 1988). Intellectual impairment in these patients is also characterized by deficits in visual/motor integration, and abstracting ability. Reduced mental alertness, fatigue, and diminished perceptual-motor coordination are also frequently cited as characteristic clinical features (Hart & Kreutzer, 1988). In addition, depressed mood and personality and mental status changes are likely to be present (Hart & Kreutzer, 1988), however, higher levels of depression are not consistently associated with impaired cognitive functioning (Wolcott et al., 1988). Chronic haemodialysis may ameliorate, at least temporarily, some of the intellectual symptoms of uremia, such as memory, attentional impairments, and mood. Although formal psychometric testing has also revealed improvements in memory and attention immediately after a dialysis session, many of the symptoms of uremia are incompletely reversed by chronic haemodialysis (Wolcott et al., 1988).

Intellectual functioning in uremia and chronic haemodialysis treatment has been assessed in a number of studies and with a wide array of neuropsychological tests. The findings of superiority of verbal over performance IQ scores combined with relatively low scores on Digit Symbol and Block
Design subtests of the Weschler test are suggestive of, and consistent with, cortical impairment (Hart & Kreutzer, 1988). Interestingly, a relationship in the positive direction between overall sickness level (defined in part by serum creatinine) and WAIS performance was demonstrated by Trischmann and Sand (1971).

Studies have shown that psychological evaluations with respect to intellectual function in renal dialysis patients have played an important role in both selection procedures for receiving dialysis or transplantation, and making recommendations to improve rehabilitation after renal failure. Some studies (Rabinowitz & van der Spuy, 1978, quoted in Osberg, 1982) have shown that the less intellectually endowed patients may be rejected more frequently for chronic dialysis.

Overall, dialysis patients generally perform better on tests of intellectual and cognitive functioning than non-dialyzed renal patients (Hart & Kreutzer, 1988). However, clear, consistent evidence exists demonstrating global cognitive deficits in dialysis patients relative to medical or normal controls independent of the effects of short term fluctuations in uremic status (Hart & Kreutzer, 1988). Osberg (1982) cautions against over generalization of the results in this area. He points out that in addition to cortical damage, the psychomotor slowing that is suggested by lowered performance subtest scores can be caused by a number of other factors, including peripheral neuropathies, reduced visual acuity, and emotional factors such as depression (Osberg et al., 1982).
There are numerous methodological problems in this body of literature. Differences in sex composition of the various groups of patients may have led to inconsistent findings, as a significant relationship between IQ and adjustment was found by some researchers for male patients only (Osberg et al., 1982). Most researchers fail to relate their findings to length of time on particular treatment regimens, the characteristics of the disease, such as its progression, or level of severity, or co-morbid conditions and neuropsychological symptoms that might be expected to have some bearing upon manifestations of personality characteristics.

In summary, results of intelligence testing appear to demonstrate consistent discrepancies between verbal and performance portions of the WAIS for predialysis patients. However, these do not conclusively demonstrate organic brain damage, and there may be other explanations for this including psychosocial factors and factors related to comorbid conditions (Osberg et al., 1982). Attempts to explain the relationship between intelligence and adjustment to chronic dialysis have produced divergent results, suggesting that the association between the two variables is complex and mediated by other unexplained factors (Hart & Kreutzer, 1988).

2.2.2 Depression:

Much of the psychonephrology literature to date has been concerned with depression, especially in chronic haemodialysis patients, and many studies have documented the problems of accurately diagnosing depression in ESRD (Wise 1974; Yanagida and Strelzer 1979; Kutner et al., 1985; Barrett et al.,
1990). Rates of depression in dialysis patients have varied from 5% to 50% across studies (Smith et al., 1985; Levenson & Glocheski, 1991). In some cases, over half of the patients were reported to be moderately or severely depressed (Kaplan De-Nour & Czaczkes, 1976), while others reported only 13% of their patients as being even slightly depressed (Farmer et al., 1979). The diagnosis based on DSM-III criteria for major depression tended to be lower and varied from 5% (Smith et al., 1985) to 22% (Petersen et al., 1991), and much higher rates were evident when self-report measures were used (Smith et al., 1985). Although prevalence rates for depression were higher than those found in community-based samples, some researchers report that they are generally no higher than rates found in patients with other chronic medical illnesses (Katon & Sullivan, 1990; Lowry & Atcheson, 1980; Reichsman & Levy, 1972; Smith et al., 1985; Wright et al., 1966).

The broad range of prevalence rates documented in the literature may be explained by the vicissitudes of diagnosing depression. For example, diagnostic difficulties may be based on the prominent place somatic symptoms such as fatigue, anorexia, sleep, and bowel disorder play in establishing the diagnosis of depression, and the possible roles physical illness and medical therapy may play in producing symptoms (Petersen et al., 1991). In particular, with a dialysis population, unstable test results may well be a function of the patient's progressive or fluctuating organicity, yet many studies have failed to account for this (Foster & Cohn, 1973). Unstable test results over time may also be a reflection of the stages of adaptation to chronic hemodialysis. It has also
been suggested that in ESRD, and other chronic physical illnesses (Sensky, 1990; Sensky, 1992), symptoms of depression are more common in those patients with a past history of depression (Craven et al., 1987; Sensky 1989; Sensky 1989). Diagnostic and prognostic difficulties also appear to be related to inadequate control over the effect of illness severity (Petersen et al., 1991).

As in any other condition, or in the general population, it is important that depression be recognized and treated (Craven et al., 1987; Sensky, 1989; Sensky, 1989), particularly since there has been some evidence that depression may be associated with poor compliance with, or withdrawal from, active treatment (Rodin et al., 1981), thereby impairing the general medical status of the patient (Abram et al., 1971). Others have also suggested that depression is associated with poor outcome and a notably higher mortality rate (Ziarnik et al., 1977; Farmer et al., 1979; Farmer et al., 1979; Burton et al., 1986). Ziarnik et al. (1977) found that patients who died within the first year were more likely to have been depressed (on the Minnesota Multiphasic Personality Inventory administered prior to beginning haemodialysis) than those who survived longer. Other mortality studies also found that age and depressive symptoms on the Beck Depression Inventory were better predictors of survival than medical variables (Shulman et al., 1989; Ziarnik et al., 1977; Eisdrath, 1969). However, findings in the opposite direction are reported in other studies (Glassman & Seigel, 1970; Foster & Cohn, 1973; Husebye et al., 1987; Eggers 1990). In fact, Devins et al. (1990) found that in their mixed (haemodialysis, CAPD, transplant) group, those who described their lives as happy overall had
the shortest survival times. Depression has been associated in the literature with diminished survival of patients treated with HD for ESRD (Petersen et al., 1991), but less is known about depression and survival in CAPD patients.

Similar contradictions have been encountered in comparing psychiatric morbidity among patients on dialysis and those who have received transplants. Some studies have reported lower rates of psychiatric morbidity after transplantation, while others have found little difference between transplant recipients and dialysands in this respect (Kalman et al., 1989). Prospective, longitudinal investigations have found that while transplant recipients whose grafts fail tend to experience more psychological problems (Rodin & Voshart 1986), successful transplantation is associated with less psychiatric symptomatology (Sensky, 1989; Sensky, 1989).

Numerous attempts to compare rates of depression, or of psychiatric morbidity associated with different forms of dialysis are documented in the literature. The mix of treatment groups makes interpretation difficult because most of the differences in psychosocial adjustment have been demonstrated between patients receiving different modalities of treatment of ESRD without attempting to match patient groups on time or type of treatment or treatment locations (Hinrichsen et al., 1989; Sensky, 1989; Sensky, 1989). In addition, the degree to which unmeasured severity differences among groups accounts for survival differences has not been firmly established (Ziarnik et al., 1977; Burton et al., 1986; Shulman et al., 1990).
Depression could be affected by a variety of factors that are themselves influenced by disease severity (Griffin et al., 1995). Eitel et al. (1995) found that with increases in disease severity, a relationship between actual, or behavioral, control over treatment and depression becomes apparent. Specifically, they found that although control over treatment may be beneficial for some patients, severely ill patients may be overburdened with added responsibility for self-care and respond negatively with heightened depression. Controlling for age and social desirability strengthened this effect. Eitel et al. (1995) concluded that while it may be preferable for patients to have as much control over treatment as possible, such control appears to undermine adjustment as illness becomes increasingly severe (Eitel et al., 1995).

The relationship between disease severity and depression also appears to depend in part on type of dialysis (Sacks et al., 1990; Griffin et al., 1995). Griffin et al. (1995), using a severity index for ESRD patients (ESRD-SI; Craven et al., 1991) found that disease severity scores were positively related to depression in CAPD patients but not in HD patients. (Note: the ESRD-SI will be described in greater detail in a subsequent section.) Similarly, Sacks et al. (1990) found that severely ill CAPD patients were less well-adjusted than their HD counterparts.

It appears that illness intrusiveness is greatest for CAPD patients, who have more control, but must administer their treatment daily while continuing with their everyday activities and work. They may be less able to separate their treatment from their nontreatment life, in contrast to HD patients who receive
treatment within distinct time blocks each week (Eitel et al., 1995). Interestingly, in (HD) patients who have less control over treatment, depression scores decreased with illness severity, with severely ill patients reporting the least depression, perhaps due to a concomitant increase in quality and quantity of interactions with medical staff, and support from other patients (Eitel et al., 1995). For example, medical staff often assume that home and CAPD patients are healthier and better adjusted than their hospital counterparts, and these assumptions may lead to increased expectations of self-sufficiency (Eitel et al., 1995) and greater accountability for negative outcomes (Brownell, 1991). This may be perceived as burdensome by the patients, and may in fact undermine their sense of control and prevent them from getting the support that they need (Eitel et al., 1995). These results imply that only when illness becomes severe or poses a serious threat to the individual does behavioral control over treatment affect psychological adjustment. It may also be that psychosocial factors are more predictive of depression in ESRD patients than are physical illness variables. However, the importance of contextual variables such as severity of illness when examining control and depression should not be overlooked.

Although these findings provide further evidence that negative outcomes may often be associated with increased control under certain conditions, at the same time, due to current fiscal pressures, medical patients are increasingly expected to take more responsibility and control over the treatment of their illness (Eitel et al., 1995). This is seen as a viable way of controlling rising
health care costs as developments have made treatments which patients can carry out themselves available (Eitel et al., 1995). The strong cultural ideology of individual responsibility and autonomy in western societies also places a high value on caring for oneself, and places additional burden on severely ill patients who find it increasingly difficult to care for themselves (Eitel et al., 1995). Some have found that high support, especially by patient partners, buffered against the effects of depression in in-center haemodialysis patients (Daneker, 1996). This was true regardless of physical impairment and moderated compliance with medical regimens especially among those with greater impairments (Shidler, 2000). These findings suggest that psychosocial support assessment and intervention may counteract the difficulties of adjustment to dialysis treatment. The degree to which illness severity may moderate this effect was not investigated.

Overall, there is little agreement about the impact of depression on outcome in ESRD, and the long term effects of depression on the course of ESRD are largely unknown (Petersen et al., 1991).

2.3 Compliance

Specifically, compliance concerns the patient’s adjustment to the demands of both the illness and its treatment, and refers to his or her adherence to the prescribed medical regimen. Successful treatment of ESRD requires, in addition to dialysis, the cooperation of the patient in that he or she has to maintain a strict diet, restrict fluid intake and take various medications
(Morduchowicz, 1993). Failure to adhere to treatment recommendations may cause the patient’s health to suffer (Ferraro et al., 1986).

Noncompliance has typically been regarded as deviant (Ferraro et al., 1986). However, a review of the literature indicates that at least one-third of haemodialysis patients do not comply with physicians’ recommendations, thus accelerating a decline in their physical health (Hartman & Becker, 1978). Poor adherence is a problem in transplant recipients as well as those on dialysis, although it has been studied much more extensively in the latter group (Sensky, 1989; Sensky, 1989).

Despite the alleged frequency of non-compliance among hemodialysis patients and the widespread use of the noncompliance label among medical staff, there is little agreement among researchers as to how the phenomenon of compliance should be measured (Ferraro et al., 1986). Many approaches have been used to quantify the compliance of ESRD patients including questionnaires answered by staff and patients, and blood tests (Hartman & Becker 1978). Measures of compliance typically rely on objective markers such as weight gain, or physiological measures (e.g., BUN, creatinine clearance, serum potassium levels). With few exceptions (Manley & Sweeney, 1986; Christensen et al., 1992; Morduchowicz et al., 1993), researchers have defined inadequate adherence on the basis of arbitrary cut-off values of these variables. However, the cutoff points have been criticized as being too low, resulting in over-identification of noncompliant patients (Levenson & Glocheski, 1991; Sensky, 1993).
Hartman and Becker (1978) note that there are major differences in defining who is compliant, depending upon which measures are used. Even in their own study, they observed compliance rates varying from 39% of the sample when assessed by phosphorus levels, to 74% when assessed by potassium levels, to 78% when assessed by interdialytic weight gain (Hartman & Becker, 1978). Despite these differences, there is little agreement as to which indicators are more inclusive or exclusive in the definitional process (Hartman & Becker, 1978). Not surprisingly, there is a great variety of often contradictory descriptions of the non-compliant patient (Ferraro et al., 1986). For example, some studies (Blackburn, 1977; Boyer et al., 1990; Sensky, 1996) found that women were more likely than men to be compliant, but Hartman and Becker (1978) found the opposite. The following variables have also been associated with noncompliance: (1) paranoid symptomatology; (2) depression; (3) level of frustration tolerance; (4) “acting-out” tendencies; (5) suicidal tendencies; (6) denial of the sick role; (7) obsessive compulsive traits; and (8) external orientation on health locus of control (Kaplan De-Nour et al., 1968; Kaplan De-Nour & Czaczkes, 1976).

Much of the literature on compliance focuses on psychosocial factors implicated in compliance, in particular, the role of depression in adherence problems. An association has been reported between poor adherence and depression (Tracy et al., 1987); however, this has not been supported elsewhere (Yanagida et al., 1981). Symptoms of depression are, however, common among people on haemodialysis, and when present, may alter locus-
of-control beliefs and other cognitions (Devins, 1990). Reported associations between adherence and locus of control or health beliefs may in fact be due to depressive symptoms according to some (Devins, 1990), but again, this is contradicted by others (Schneider et al., 1991). Other cognitive factors, such as the individual’s capacity for self-control, may also play a role (Sensky, 1996).

Recently, Baadsager Chambliss (1997) studied the effects of health locus of control, social support, and illness severity with regard to depression and compliance in a sample of black HD patients. She found that within the high illness severity group, patients who had high internal locus of control orientation were significantly less compliant than patients with a low internal locus orientation (Baadsager Chamblis, 1997). This suggests that internality is detrimental to patient adjustment in the context of uncontrollable conditions such as severity of illness (Baadsager Chamblis, 1997). Baadsager Chambliss (1997) also concluded that health locus of control, social support, and illness severity do not strongly interact in terms of determining depression and compliance in black HD patients. This study relied on Plough’s (Plough et al., 1985) severity of illness coefficient, a measure of disease severity that contains psychosocial confounds as will be discussed in later sections.

Some studies have associated compliance with good social supports (Steidl et al., 1980). Other researchers have found that good social supports, or good social adjustment, appear to have adverse influences on dietary and fluid compliance (Hartman & Becker, 1978; Sensky, 1996). However, these studies also found that patients with a psychiatric history and who were married
showed better compliance. This may be due to a tendency of spouses to be more active in promoting adherence where there is a history of psychiatric problems (Hartman & Becker, 1978; Sensky, 1996). However, other research contradicts these findings (Boyer et al., 1990; Christensen et al., 1992).

Previous research has suggested that with increasing age, adherence to diet (Boyer et al., 1990; Morduchowicz et al., 1993), and fluid restriction (Bame et al., 1993) may improve. While some studies imply that elderly patients have a better overall compliance than younger patients, Morduchowicz (1993) found this to be case for dietary compliance only. Older patients tend to be more consistently compliant if they were depressed and believed that others could influence their health, but less compliant when not depressed, with good social adjustment (Sensky, 1996). Others have reported decreased compliance with increased time on dialysis (Boyer et al., 1990; Morduchowicz et al., 1993). This may be because recent hemodialysis patients also tend to be characterized by better kidney functioning, and because creatinine levels are more likely to be sensitive to residual kidney function, this residual function is probably more important than social factors in shaping the relationship between compliance and the amount of time on dialysis (Ferraro et al., 1986). While it is possible that locus of control beliefs have a differential impact on compliance depending on age, with older patients exhibiting less desire to be actively involved with their treatment (Cassileth et al., 1980; Strull et al., 1984; Ende et al., 1989), the increasing severity of the disease with age may affect both locus of control beliefs and compliance (Wolcott et al., 1988; Wolcott et al., 1988).
On the whole, compliance appears to be a multidimensional construct. Studies have shown that it may be affected by age, marital status, sex, ethnicity, type of dialysis, disease severity, educational level, and socioeconomic status (Morduchowicz et al., 1993). However, studies of compliance tend to be plagued by many of the same methodological problems common to those studies focusing on psychosocial factors, resulting in inconsistent published results in both areas (Sensky, 1993).

Because of contradictory results of published work, firm conclusions are impossible despite the considerable body of literature on factors related to compliance with dietary and fluid restrictions. Notwithstanding, serious decisions are often made on the strength of published research. For example, very poor adherence while on dialysis is one factor used to determine the patient's priority for transplantation (Sensky, 1993). In short, prior research paints contradictory pictures of the compliant HD patient. Most studies fail to adequately control for the effects of illness severity, and when they do, they utilize measures that contain non-disease variables thus introducing a confound, and placing results into question.

2.4 Quality of Life Research in ESRD

Generally, it is believed that there are three major factors influencing quality of life in the medically ill: (1) functional capacity (the abilities to perform activities of daily life, social function, intellectual function, emotional function, and economic status); (2) perceptions (levels of well-being and satisfaction with life); and (3) effects of symptoms of disease with resultant impairment (Fava,
1990). However, quality of life is a very complex concept, and there is, to date, no agreed upon operational definition on which research and measurement scales are based (Fava, 1990). Quality of life may refer to a variety of topics such as physical and psychological complaints, feelings of well-being, sexual functioning and daily activities (Fava, 1990).

Numerous researchers have measured quality of life using simple measures of life satisfaction, such as Campbell’s Quality of Life scales (Simmons et al., 1984; Evans et al., 1985; Evans et al., 1990) However, the use of such instruments is problematic because they were developed for use in community samples, having never been validated for use with a chronic, physical illness population. Most importantly, ratings on the Campbell’s scales correlate very highly with measures of depression (Sensky, 1993). As a result, these instruments are in fact, measures of affective disturbance (Sensky, 1993).

Affective disturbance such as depression influences subjective quality of life in ESRD, as in physical illness generally. However, its relationship to chronic illness, or to the severity of the illness, is far from clear (Sensky, 1990; Sensky, 1992). In other words, a patient might report low life satisfaction either because of the impact of the disease despite treatment, or because of depression (Sensky, 1990; Sensky, 1992). Furthermore, major and life-threatening illnesses do not necessarily compromise an individual’s quality of life. On the other hand, what is viewed by physicians as a minor ailment may entail life-long disability to the patient (Yanagida & Strelzer 1979; Greenfield &
Nelson 1992). Patients with similar diseases vary considerably in their physical health status. As detailed earlier, some renal patients have relatively few medical problems beyond the renal disorder whereas others have numerous disorders either independent of, or consequent to, renal disease (Greenfield & Nelson 1992). Without incorporating the appropriate controls, most studies are unable to separate the influence of these variables, particularly when the methodology includes the use of self-report measures.

Quality of life has been the subject of much research. In particular, a great many studies have attempted to investigate the impact of different forms of renal replacement therapy (Sensky, 1993). Because there can be marked sociodemographic and clinical differences between dialysis and transplant samples, between those on home and unit haemodialysis, and between those on CAPD and haemodialysis, it is crucial that the effects of different case-mix be controlled (Plough et al., 1984; Sensky, 1993). Few researchers have attempted to match patient groups (Sayag et al., 1990), or to statistically control for relevant variables (Evans et al., 1985; Koch & Muthny 1990). Not surprisingly, there have been many conflicting results reported in the literature. For example, there have been reports that transplant recipients have better quality of life than patients on dialysis (Simmons et al., 1984; Koch & Muthny, 1990). Other studies found little difference between the two populations (Kalman et al., 1989), especially if compared to home dialysis patients who, in turn, fare better than hospital or dialysis unit patient (Evans et al., 1985). A recent study (Martin & Thompson, 2000) found that psychological factors,
particularly depression were much stronger determinants of quality of life in CAPD patients than biological indices of dialysis adequacy.

Despite the intuitively obvious relationship between disease progression, severity and quality of life, there are very few quality of life studies that have incorporated a valid and reliable measure of illness severity. Those studies that have done so (e.g., Rocco et al., 1997) found a significant relationship between disease severity and impairment in quality of life. Similarly, other investigators demonstrated that in ESRD, chronic dialysis patients have a greater decrement in quality of life and more psychological distress from medical symptoms than patients in earlier stages of the disease, suggesting that as the degree of renal dysfunction increases, the impairment in quality of life increases (Kaplan & Mehta, 1994). However, none of these studies made use of validated, reliable indices of disease severity, relying instead on the Symptom Checklist 90R (Kaplan & Mehta, 1994), or a self-report scale rating severity of symptoms on a scale of 0 to 4 (Rocco et al., 1997).

As is the case in dialysis research, methodological inconsistencies in the transplantation literature make efforts to compare treatments for CRF/ESRD notoriously difficult. Because of this difficulty, the sole, or at least main conclusion from research to date appears to be that, in terms of rehabilitation, adjustment or quality of life, some people do better than others, regardless of the type of treatment (Sensky, 1993).
2.5 Other Psychosocial Factors in ESRD

The psychological mechanism of denial has also been of interest to ESRD researchers particularly since the introduction of dialysis, and is generally considered to be important in the course of chronic dialysis patients (Glassman & Seigel, 1970), as well as in the recognition and management of psychiatric disturbance in ESRD (Sensky, 1993). However, investigators are divided as to the impact of denial. Glassman and Siegel (1970) found that extreme denial improved survival on dialysis, while Sviland (1972) suggested that successful dialysis patients had a less, but more adaptive level of denial. It has also been suggested that denial may be an adaptive coping strategy after a failed transplant. However, this has been contradicted by reports of successful group interventions in which the influence of denial has been minimal (Sensky, 1993). At the other end of the spectrum, Cummings (1970) has identified denial as a potential killer for dialysis patients. Ziamnik et al. (1977) compared predialysis MMPI scores of patients who died before the end of the first year of dialysis and two groups who had been on dialysis for 3 to 11 years. Those in the early death group had significantly higher elevations on the neurotic triad and the Psychasthenia scale, suggesting a relationship between internalized stress and morbidity (Ziamnik et al., 1977). The contradictory results are likely the result of methodological inadequacies, including comparisons of dissimilar treatment modalities, heterogeneous samples, and the failure to control for potentially confounding variables such as severity of illness.
Although few studies attempt to differentiate patient groups on the basis of illness severity, those studies that purport to include such differentiation have yielded mixed results. For example, Trieschmann and Sand (1971) attempted to differentiate groups of predialysis patients by assigning them to “most sick” and “least sick” categories. The groups were split into ‘most’ and ‘least’ sick by creatinine levels. They found no differences between a “most sick” and a “least sick” group of predialysis patients on the MMPI. They concluded that there was little evidence for a relationship between MMPI results and uremic toxicity (Trieschmann & Sand, 1971). This study focused on a single measure of “sickness”, and did not control for medication, other conditions, age, or other demographic differences. Although attempting to control for illness severity, the researchers did so in a very limited sense by using only one measure. The results of this study contradicts the findings of other researchers who postulated a strong relationship between internalized stress and morbidity, but who did not attempt to control for illness severity (Ziamik et al., 1977).

2.6 Voluntary Termination of Treatment and Suicide

Suicide and withdrawal from life support treatment are controversial issues. It has been estimated that at least 6 percent of decisions made on a medical ward involve deliberations about withdrawal from life sustaining treatment (Neu & Kjellstrand, 1986). The annual mortality rate in the US due to voluntary withdrawal from dialysis has been reported to be approximately 2.1% (Held et al., 1987; Eggers, 1990), with the percentage of death from withdrawal from treatment ranging from 0.1% among the 15- to -24 year age group to 9.9%
among the over 85 age group (Eggers, 1990). The practice of stopping dialysis has increased over time but correlates with an increase in the proportion of older and diabetic patients receiving dialysis (Neu & Kjellstrand, 1986).

Voluntary withdrawal increases with advancing age, and is also related to diabetes. Indeed, these factors appear to be the most important risk factors for discontinuation. Treatment was withdrawn more frequently in older than in younger nondiabetic patients, and more often in young diabetic patients than in young nondiabetic patients (Neu & Kjellstrand, 1986). Among diabetic patients, no other complications present at initiation of dialysis seem to be important. Withdrawal was twice as common in nondiabetic patients with other degenerative disorders, in patients receiving intermittent peritoneal dialysis, and in patients living in nursing homes (Neu & Kjellstrand, 1986). Patients whose renal failure was attribute to diabetic nephropathy were more likely to die due to voluntary withdrawal than were other patients, 2.5%, and 1.9%, respectively (Eggers, 1990).

Voluntary withdrawal also appears to be related to race. Among racial groups, voluntary withdrawal from dialysis is most common for whites, 2.7%; least common for blacks, 0.9%, with intermediate rates for other groups (Eggers, 1990). Overall, survival rates for whites are 5% to 6% lower than for other racial categories (Held, 1997), a finding that may be due to unmeasured severity differences between the racial groups (Eggers, 1990).
Although non-compliance is in itself a life-threatening behavior, high rates of actively suicidal behavior as well as completed suicide have been reported for dialysis patients (Abram et al., 1971) and post-transplant patients (Washer et al., 1983). Some have reported that the suicide rate among dialysis patients may be more than 100 times that of the normal population and much higher when deaths from overt noncompliance are included (Abram et al., 1971). However, these studies likely overestimated suicide prevalence by not distinguishing rational treatment withdrawal from suicide. This is a complex issue to analyze empirically because death due to termination of treatment is usually recorded under the disease being treated, rather than withdrawal of treatment (Washer et al., 1983).

It is very difficult to accurately assess suicidal intent, and even to ascertain whether a death is the result of suicide in this group of patients. The true rate of suicide in dialysis has not been established systematically, nor has there been sufficiently careful attention paid to the psychological factors that may affect the decision to withdraw from treatment (Levenson & Glocheski, 1991). For example, it may be that the critical factor influencing some patients to choose to discontinue their treatment is their perceptions of their prognosis (Hirsch, 1989), an assessment which may differ significantly from an objective assessment of the status of the disease (Sensky, 1990; Sensky, 1992). Studies controlling for illness severity in patients who have voluntarily discontinued treatment would help to clarify this issue.
In summary, the literature consists of largely of contradictory evidence most of which is likely due to the absence of some means to isolate and measure sources of error. For example, some of the reasons for inconclusive research into mortality rates, the need for home versus hospital dialysis, and determining eligibility for transplantation may be in part impacted by variability due to differences in illness severity.

2.7 Summary: Methodological Problems in the Psychonephrology

Research Literature

Until the introduction of HD, ESRD was considered a fatal and irremediable condition (Devins et al., 1981). Although the treatment of chronic renal failure has greatly advanced over the years, the mortality rate continues to be very high (Devins et al., 1981). Psychiatric morbidity is also high relative to other chronic illnesses (Sensky, 1996). A variety of causes have been proposed for the high incidence of psychiatric morbidity and suicidal tendency found in the haemodialysis patient population (e.g., organicity, psychosis or acute delirium or both, premorbid anxiety, depression, and denial) (Sensky, 1993; Sensky, 1996).

Renal disease is associated with a number of conditions (e.g., uremia, anemia, electrolyte disturbances, and underlying systemic diseases, such as systemic lupus erythematosus) that may mimic depressive states or cause organic mood disorders, and thus, the direction of causality is not well-understood (Barrett et al., 1990). These conditions are in turn linked to several
factors including compliance (Sensky, 1993), length of time on dialysis (Reichsman & Levy, 1972; Hart & Kreutzer, 1988), and the extent to which uremia is controlled (Barrett et al., 1990). Patients may also be taking medications designed to treat concomitant conditions (e.g., corticosteroids, anti-inflammatory agents) that have depressive side effects (Hart & Kreutzer, 1988).

There has been some evidence that co-morbidity and, in particular, the degree of severity of co-morbidity have an impact on haemodialysis patient survival (Keane & Collins, 1994), yet there are few severity indices in the literature that make use of objective, physiologically based measures in their assessment of health status. Instead, a number of existing illness severity indices mix physiological and psychosocial, non-disease variables, thus introducing confounds that obscure results. This is particularly significant since the prevalence of co-morbidity in the dialysis population appears to be increasing (Storset et al., 1995).

Various researchers have developed ESRD severity measures based on analyses of differential patient survival. For example, Plough and associates (1985) identified five risk groups that differentially predicted survival in ESRD patients. A problem with Plough's (1985) measure of ESRD severity is that it does not reflect the patient's current severity of illness. In addition, the severity coefficient includes subjective psychosocial variables as comorbid conditions. As a result, this confounds the use of Plough's measure of illness severity in studies examining psychosocial variables in ESRD patients.
Although recovery from chronic illness could be greatly facilitated by clinicians, the lack of reliable information on issues such as differential effects of the various CRF/ESRD treatment modes, changes in the quality of life, and burden of illness potentially limits the scope and usefulness of medical efforts (Fava, 1990). For example, it has been demonstrated that chronic HD patients have more debilitating neuropsychological problems as compared with CAPD patients (Hart & Kreutzer, 1988; Wolcott et al., 1988; Wolcott et al., 1988; Fava, 1990). In addition, because treatment for ESRD is necessary for survival, the degree to which patients have control over their treatment may have an effect on psychological adjustment to illness (Eitel et al., 1995), as well as on policy decisions. For example, although self-care options may be empowering to the mildly ill and be more economical, forcing severely ill patients out of the hospital setting to care for themselves may do more harm than good in terms of psychosocial adjustment and quality of life (Eitel et al., 1995). Yet, encouraging home treatment is becoming a growing trend (Eitel et al., 1995). The need to accurately measure the negative effects of interpersonal expectancies associated with different degrees of control is particularly important given the current political and economic climate that strongly encourages an ethic of individual responsibility for health (Eitel et al., 1995).

There has been much research into the many aspects of renal disease and its treatment. Renal disease has been studied from the point of view of treatment effectiveness, compliance, and in particular, psychiatric morbidity, to name but a few. Overall, there does not appear to be a coherent theory to
explain the high incidence of psychiatric morbidity in this medical population. The lack of clarity in the research literature is likely due to confounding variables that are present, but not measurable by psychological tests, and whose effects, if not isolated and identified can inflate the error in the data. Such error may in fact be systematic variance in the data due to some unaccounted for variable. For example, a variety of factors are known to influence research with CRF/ESRD patients (e.g., treatment type, age, dialysis duration). In particular, a serious problem facing researchers studying most aspects of chronic endstage renal disease is that of the wide variability of the physical health status of renal patients. The severity of renal failure, including comorbid conditions, may of itself influence the degree to which a patient can effectively adjust to treatment restrictions, learn coping strategies, and benefit from various medical interventions.

Variability of disease severity across CRF/ESRD patients contributes significant noise to the data obtained from such patients, and if not taken into account, or treated as error variance, can act as a suppressor variable which potentially obscures true effects. Specifically, treating all CRF/ESRD patients as a homogenous group with respect to physical condition in the face of such known variability may suppress the observed relationships between variables of research interest (e.g., renal problems and compliance, quality of life, or treatment effectiveness). As a result, these variables may have the appearance of being correlated with the outcome less strongly than is actually the case.
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There are many such uncertainties in this literature with the result that researchers may interpret findings as disconfirming a given hypothesis without taking into account the influence of disease severity on the outcome. Without controlling for disease severity, it is not possible to determine which of these variables is influencing patient mood, and thus, what medical or psychosocial intervention would be of greatest assistance to the patient.

Appropriate, effective interventions can be only be undertaken and evaluated with confidence if a patient’s health status can be accurately assessed with respect to impinging psychosocial as well as physiological variables. Psychosocial research on chronic illness must therefore better control for disease severity in order to test hypotheses about psychological and social factors (Sacks et al., 1990). A numerical measure of illness severity in renal patients would serve as a control measure to isolate potentially confounding variables. However, up to now, this has received minimal attention and few instruments exist that address contextual variables such as severity of illness in a valid and reliable way. Although there have been promising developments in the area of severity of illness measures, there remains a tendency in research with ESRD patients to use predictors of mortality as a proxy for disease severity (e.g., Plough, 1985) (Griffin et al., 1995), including physical comorbidity (e.g., diabetes and heart disease), demographic variables (e.g., age and race) and psychosocial variables (e.g., depression) (Hutchinson et al., 1982; Plough et al., 1985). This trend may be in response to evidence
that the cause of death in dialysis patients is most commonly due to a concurrent illness (Santiago & Chazan 1989).

Non-disease factors however are not unique indicators of disease severity and do not directly measure the current disease status of the patient. Measures that include non-disease factors may be inadequate for testing psychosocial hypotheses because the inclusion of variables unrelated to organic conditions may confound such analyses (Griffin et al., 1995). These circumstances have significantly impacted the results of much research on renal patients, and decreased the measurement and research potential of psychometric tests. Once this systematic variance is identified, quantified and controlled for, it could increase the power of research instruments.

The following section of the literature review will briefly review some present measures of health status and illness severity before dealing specifically with measurement of illness severity in renal patients.

2.8 Health Status Measurement

2.8.1 Health Status Measurement: An Overview

Health status measurement may be defined as the qualitative and/or quantitative evaluation of the health of an individual or a patient. It can include traditional biologic indicators, but emphasizes indicators of physical functioning, mental health, social functioning, and other health related concepts such as pain, fatigue, and perceived well-being (Greenfield & Nelson, 1992).

Health status measures are most often used in clinical settings to describe the natural course of disease and the impact of disease on health
status (e.g., understanding the course of disease and the process of aging), to evaluate treatment effectiveness (Breslow, 1989) and the quality of care (Greenfield & Nelson, 1992), usually with specific attention to the restrictions in a person’s ability to function (Mosteller et al., 1989). Some health status measures are geared towards assisting the clinician in the individual management of patients, while others are being used as outcomes in the assessment of quality of care for groups of patients across physicians, and health care plans (Goldberg & Pantell 1992).

Health status tends to be assessed in three main ways. Physicians assess health status by means of diagnosing individual disease states or condition. While this is necessary, it oversimplifies the physiological complexity of most chronic illnesses which are characterized by at least one other concomitant condition. There are measures of health status that look at models of functioning. However, this perspective is too broad in that it attempts to measures many individuals across conditions. Models of functioning are insensitive to individual responses to disease progression or treatment outcome, or to life-threatening illness states. Finally, there are disease specific measures of health status. Measures such as the Endstage Renal Disease - Severity Index (ESRD-SI) (Craven et al., 1991), or the Severity of Renal Disease Scale (SORDS) (Baltzan et al., unpublished manuscript) measure health status across various diseases and functional limitations.

Health status instruments tend to be divided into either generic or disease specific categories of measures. There is already a large number of
these measures available and in use, either in clinical practice, or research or in both venues, and this number is steadily growing. Indeed, the sheer number of health measures available poses a problem for decision makers.

Generic health status measures are generally used by policy analysts involved in health services evaluation, resource allocation, or population comparisons. Research using generic health status measures typically focuses on health status change across different diagnostic groups, usually using large sample sizes. Such measures are designed to be broadly applicable across types and severities of disease, across different medical treatments, and across cultural subgroups (Patrick & Deyo, 1989). These measures may yield either a single index value, or a profile of interrelated scores.

Generic measures of patients’ health, such as quality of life and perceived health status, have been shown to be highly stable over time and consistent with some concurrently measured clinical indicators of health (Stewart et al., 1988). These measures might better reflect the total impact of chronic disease on the individual including both systemic complications and comorbid conditions. However, forecasting patients’ risk for poor health outcome using generic health status measures alone may be problematic (Kaplan, 1987). Two patients at the same level of functioning at the same time may have very different prognoses for remaining at that level, depending on the reasons for their limitations. Different people respond differently to physical signs and symptoms. Patients may also place a different value for certain levels
of functioning. In addition, some diseases have ‘silent’ symptoms, and have relatively little effect on the individual (Read et al., 1987).

Disease specific measures are those that are designed to assess specific diagnostic groups or patient populations. Not all specific measures are disease related, but may instead be specific to certain conditions such as back pain, or related to well-established physiologic measures. The goal of disease specific instruments is the measurement of clinically important changes that have been detected following an intervention of known efficacy (Patrick & Deyo, 1989) Some recommend that disease-specific measures of health be used routinely as supplements for the generic health measures (Mosteller et al., 1989).

Disease specific measures alone may only imperfectly reflect disease severity, and they may not reflect complications related to the disease and to comorbid conditions, particularly if limited to physiological data. They may also be to substantial measurement error. However, if it were possible to scale the severity rating of the various physiologic measures as representative of different comorbid states on a common underlying dimension of illness severity, illness could be measured more accurately when used in the context of a disease specific model. This, in turn, would allow the distinct contributions of psychosocial factors to be delineated (Eberl et al., 1976).

The relationship between comorbidity and outcome is particularly evident in endstage renal disease. It has been well-documented that renal patients with more complex medical conditions have lower survival rates within any age
group compared with patients who were free of complicating medical problems (Keane & Collins, 1994). A systematic method of interpreting these values in relation to severity levels for various diseases would be of great practical value (Wenneker et al., 1990; Wenneker et al., 1991).

It is obvious that illnesses vary in stability. However, most health status measures, both generic and disease specific, tend to be static, reflecting observations over a brief period, such that conditions with different courses may seem equally severe on any single assessment. In fact, diseases are often classified as either present or absent, with multiple dimensions merged into a single ordinal measure. To complicate matters further, because information about comorbidity is usually less important to an individual intervention or a single hospitalization than information on the primary condition, less information tends to be available about coexisting conditions (Wenneker et al., 1990).

2.8.2 Selected Generic Health Status Measures

There are various generic health status measures available, some of which satisfy psychometric standards. Two such measures, the Medical Outcomes Study (MOS) 36-Item Short-Form Health Survey or SF-36 (Ware, 1992), and the Sickness Impact Profile or SIP (Bergner et al., 1981) have been frequently used in the literature with specific populations. There is one generic measure of illness severity, the Severity of Illness Index or SII (Horn et al., 1983). However, the SII appears in the research literature much less frequently than the aforementioned scales, perhaps because there has been so little importance placed on isolating and measuring the impact of disease severity.
A fourth measure, the APACHE III (Acute Physiology, Age, and Chronic Health Evaluation, 3rd Edition) (Knaus et al., 1981) will also be considered. The APACHE III is a physiologically based prognostic system commonly used to assess prognosis for groups of intensive care unit admissions. The APACHE III has demonstrated good validity and reliability and is a suitable measure of progressing illness severity as it is strongly associated with risk of hospital mortality (Zimmerman, 1996).

The SIP is described as a standardized, behaviorally based instrument that measures sickness-related behavioral dysfunction in the areas of physical, mental, and social functioning (Bergner et al., 1981). It is intended to provide a measure of the effects of health care, and the impact of illness on everyday life. It has 136 items, organized into 12 categories, each representing a different component of health, and each of which describes an area of behavioral dysfunction (Bergner et al., 1981). Potential scores range from 0 to 100, with higher numbers representing greater “sickness impact” and thus poorer health. The higher the score in each area, the more that patients perceive themselves as being functionally limited (Bergner et al., 1981).

Overall, the SIP appears to be a good source of health information from a clinical perspective. As well, its construction permits analysis of subscales focusing on specific health concepts in addition to analysis of a summary score. However, it does not specifically measure well-being, being somewhat restricted by its focus on behavioral dysfunction (Read et al., 1987), and is
relatively time-consuming in that it takes approximately 30 minutes to complete (Weinberger et al., 1991).

The purpose of the Severity of Illness Index (SI) (Horn et al., 1983) is to identify sub-groups of patients that are homogeneous with respect to severity of illness. It is a generic, four-level ordinal scale (increasing severity from level 1 to level 4) determined from the values of seven dimensions rated to a patient's burden of illness (Horn et al., 1983). These dimensions are: (1) stage of principal diagnosis; (2) concurrent interacting conditions that affect hospital course; (3) rate of response to therapy or rate of recovery; (4) impairment remaining after therapy for the acute aspect of the hospitalization; (5) complications of the principal diagnosis; (6) patient dependency on hospital staff and facilities; and (7) extent of nonoperating room procedures (Horn et al., 1983).

Dimensions (1) to (3) refer to burden of illness that the patient experiences, and presents to the hospital. The sixth and seventh dimensions, dependency and non-operating room procedures, are included for internal monitoring purposes only. The last two variables reflect the response of the patient to the hospitalization (Horn et al., 1983). To obtain an overall severity index for an episode of illness, a rater scores each of the seven variables into one of four levels of increasing severity by examining the patient's medical record at discharge for that episode. The overall severity level is selected by integrating the value of the seven dimensions. No formula is given to the raters...
to combine the values of the seven variables (Horn et al., 1983). There is
evidence for reliability and validity of the SII (Horn et al., 1983).

The SII produced a simple classification that was consistent across
different diagnostic and hospital populations. Therefore, the SII may provide a
useful means of grouping patients, and could have implications for programs of
prospective reimbursement and for cross-hospital comparison studies (Horn et
al., 1983).

However, although administration is very brief (an experienced rater
takes an average of 5 to 7 minutes to rate a chart for severity purposes only),
the authors suggest a 3 day structured training program for prospective raters
(Horn et al., 1983). In addition, the SII yields ordinal results only, and therefore
cannot be used in parametric analysis procedures.

The APACHE III (Acute Physiology, Age, and Chronic Health Evaluation
- 3rd Edition) (Knaus et al., 1981) is a commonly available severity of illness
scoring system that measures acute physiological distress. The original
development of the APACHE systems (APACHE I, II and III) was based on the
association between acute changes in a patient’s physiologic balance and
short-term risk of death (Knaus et al., 1981). The APACHE III was developed to
improve upon the risk prediction available with earlier versions by reevaluating
the selection and weighting of physiologic variables while examining how
differences in patient selection for and timing of admission to ICUs related to
outcome variations across hospitals (Knaus et al., 1981). An increasing
APACHE III score (0-299) is associated with a higher risk of hospital mortality.
All three versions of APACHE have demonstrated good reliability and validity (Zimmerman, 1989).

The SF-36 was constructed to survey health status in the Medical Outcomes Study, an observational study of variations in physician practice styles and patient outcomes in different systems of care (Stewart et al., 1988). The authors’ goal was to develop a general health survey that was comprehensive and psychometrically sound, yet short enough to be practical for use in large-scale studies of patients, practice settings, health policy evaluations, and general population surveys (Stewart et al., 1988). The SF-36 survey was constructed for self-administration by persons 14 years of age and older, and for administration by a trained interviewer in person or by telephone (Ware & Sherbourne, 1992). It has 36 items, and takes 15 minutes to complete (Weinberger et al., 1991).

The SF-36 obtains the patient's self-assessment of functional status and well being in general (rather than attributed to underlying disease or to treatment). “Functional status” is operationally defined in behavioral terms, focusing on physical, role, and social functioning. “Well-being” is defined in terms of feeling states, focusing on mental health, vitality, and absence of pain. It also captures the patient’s overall rating of health in general (e.g., general health perceptions) (Ware & Sherbourne, 1992).

The SF-36 includes a multi-item scale that assesses eight health concepts: (1) limitations in physical activities because of health problems; (2) limitations in social activities because of physical or emotional problems; (3)
limitations in usual role activities because of physical health problems; (4) bodily pain; (5) general mental health (psychological distress and well-being); (6) limitations in usual role activities because of emotional problems; (7) vitality (energy and fatigue); and (8) general health perceptions (Ware & Sherbourne, 1992). Most of the items in an earlier, longer version of the scale were adapted from instruments that have been in use for 20 to 40 years, and items in the shortened (SF-36) version were selected to reproduce the parent scale as much as possible. The ‘parent’ version was then used as a criterion for the initial validation of the SF-36 (Ware & Sherbourne, 1992).

The reliability and validity of the SF-36 in terms of comprehensiveness, sensitivity to the presence or absence of disease and to severity level have been established. It has also demonstrated an acceptable ability to predict transitions in health status, expenditures, utilization and mortality (Evans et al., 1985; Ware & Sherbourne, 1992). It takes less time to administer than the Sickness Impact Profile (Bergner et al., 1981), and, although it consistently displayed a less optimistic picture of respondents’ health compared with the SIP, the instruments were highly correlated on the dimensions of: (1) overall functioning ($r = 0.73$); (2) physical functioning ($r = 0.78$); and (3) social functioning ($r = 0.67$) (Weinberger et al., 1991).

The SF-36 has been a popular measure, and it has been used in studies that have collected data in clinical settings (Evans et al., 1985; Ware & Sherbourne, 1992). It has also been used, with varying degrees of success, with ESRD patients (Ware & Sherbourne, 1992). However, for studies of
severely ill populations, the authors recommend that a supplemental battery of items be added to represent the extreme low end of the continuum defined by some health scales, in particular the physical functioning scale, which includes only one item focusing on daily self-care activities (Ware & Sherbourne, 1992). When a large proportion of the scores appear at the scale's low end, it may be necessary to supplement the SF-36 with additional items that measure basic activities of daily living (Ware & Sherbourne, 1992).

Several studies investigated the relationship of the SF-36 and other indicators of mental health, in particular the Beck Depression Inventory - 2nd Edition (BDI-II) (Beck et al., 1996), the Beck Anxiety Inventory (BAI) (Beck & Steer, 1990), and the Beck Hopelessness Scale (BHS) (Beck & Steer, 1988). Most of the correlations achieved statistical significance, however the correlations between the SF-36 Mental Health Composite scales and the Beck measures were higher (from $r = -0.31$ to $r = -0.57$) than those between the SF-36 Physical Health Composite and scales and the Beck scale (from $r = -0.07$ to $r = -0.38$) (Hays, 1998). The Mental Health Composite score was most highly correlated with the BDI-II ($r = -0.57$) and the BAI ($r = -0.54$). The correlations are negative because the SF-36 is constructed such that higher scores indicate better self-perceived health status whereas higher scores on the BDI-II indicate poorer self-reported well-being. These findings provide good evidence for both the convergent and divergent validity of the SF-36 and suggest that the Mental Health Composite score is the best indicator among the various SF-36 scales of psychological symptoms of depression and anxiety (Hays, 1998) (Ware &
Sherbourne, 1992). At the same time, however, the correlations between the SF-36, the BDI-II and the BAI show the SF-36 scales to reflect the patient’s adjustment and reaction to disease, and thus the SF-36 is not a pure measure of the physiologically determined illness severity of the patient.

2.8.3 Selected Disease Specific Health Status Measures

The term ‘disease severity’ generally refers to the extent of physiological disturbance, and the impact of the disease on the patient’s activities, or on his or her family or society (Stein et al., 1987). Measurement of disease severity is necessary to describe and compare patient samples (Craven et al., 1991), to assess and predict quality of care (Green et al., 1990), and to investigate factors which determine the clinical course of the disease (Cassileth et al., 1980). It is particularly important to measure disease severity in studies designed to distinguish psychosocial from organic determinants of physical illness (Rodin et al., 1991).

Although many disease specific physiological severity scales have been developed, they are often the reflection of clinical judgement, and lack empirically proven psychometric properties (Stein et al., 1987). Most currently available instruments are designed such that scores can be obtained in a checklist format of diseases. This list is then quantified by symptom criteria, and yields an ordinal number which is then related to the functioning of an individual. Few measures addressing illness severity have a common underlying dimension related to some aspect of that illness, such as the degree of dysfunction caused by that disease (Craven et al., 1991). As a result, such
measures lack the capability to rate the disease as a whole, or its concomitant diseases, on a common base. This is particularly critical for ESRD, for, as mentioned earlier, it has been well-documented that death in dialysis patients most commonly results from concurrent illnesses not directly measured by physiological indices of ESRD (Santiago & Chazan, 1989). Many physiological severity measures do not take into account the severity of the many other concomitant illnesses common to ESRD (Craven et al., 1991; Griffin et al., 1995).

It has been mentioned in previous sections of the literature review that the variation in physical health of end-stage renal patients likely contributes significant noise to the data obtained from such patients. This noise, if not taken into account, can potentially act as a suppressor variable in the research on renal patients. It is also possible for disease severity to act as a moderator variable, in that relationships between some variables may only be seen at low, or high levels of disease severity.

Recently, efforts have been made to address these criticisms in CRF/ESRD research and other related health research, resulting in the development of several disease-specific measures that include an illness severity component. However, most of these instruments have not been adequately investigated with respect to their psychometric properties. Two quantitative indexes of the severity of disease in renal patients have been developed and tested according to rigorous psychometric standards. The indexes, respectively called the Endstage Renal Disease Severity Index
(ESRD-SI) (Craven et al., 1991), and the Severity of Renal Disease Scale (SORDS), will be discussed in detail in the following sections.

2.8.3.1 The Endstage Renal Disease Severity Index (ESRD-SI)

The Endstage Renal Disease Severity Index (Craven et al., 1991) was developed for use in a prospective study looking at the interactions between social support and depression in renal dialysis patients. The ESRD-SI was intended to serve as a control variable so that illness severity could be assessed in a manner which minimized artefactual overlap with psychosocial variables (Craven et al., 1991). The ESRD-SI consists of 11 items representing disease categories chosen by nephrologists as those most commonly seen in patients with ESRD, and most closely associated with morbidity and mortality: (1) heart disease; (2) cerebral vascular disease; (2) peripheral vascular disease; (3) peripheral neuropathy; (4) bone disease; (5) respiratory illness; (6) visual impairment; (7) autonomic neuropathy; (8) gastrointestinal disease; (9) access and dialysis events; (10) diabetes mellitus; and (11) a single category for other diseases. Each category is rated by medical personnel on a scale of disease severity ranging from the absence of the condition to severe disease state. Severity ratings are made based on the nature of the underlying organic disease state and are independent of the patient's subjective reaction to disease (Craven et al., 1991). A series of meetings of the Toronto Hospital Nephrology Group were held to determine appropriate items for inclusion in the ESRD-SI. Ten illness categories common to renal patients were included in the index (Craven et al., 1991). Determination of scale values was not described.
The ESRD-SI is designed for use by either an independent clinician investigator with full access to clinical information or the patient’s own internist (Craven et al., 1991). Each scale contains a range of severity corresponding to descriptions and examples provided. These examples correspond to scores from 1 to 10. The scoring system gives a different range of scores for each disease item and the additive sum of items provides the total severity index (Craven et al., 1991).

Craven and his colleagues (1991) were able to demonstrate good reliability and validity of the ESRD-SI when completed by clinician investigators with full access to clinical information. Inter-rater reliability was reported to be $r = 0.92$, with a test-retest correlation of $r = 0.92$ over a 1-week period (Craven et al., 1991). It takes very little time to complete (less than 3 minutes), can discriminate subgroups which would be expected to demonstrate a higher overall disease severity (e.g., subjects on medical disability, with diabetes mellitus, or those who subsequently died during follow-up), and can predict mortality (Craven et al., 1991).

Construct validation studies have shown that the ESRD-SI is related to several important parameters of disease severity including physiological and functional indices of disease state. In particular, severe disease state was significantly related to decreased creatinine and albumin levels, and decreased functional status. These relationships were similar for both peritoneal and haemodialysis patients demonstrating that the ESRD-SI could be used for both groups of patients (Craven et al., 1991).
When scores on the ESRD-SI (Craven et al., 1991) were compared with physiological indices of severity, functional status, and psychological burden of illness in HD and CAPD patients, ESRD-SI scores were negatively associated with functional ability and positively related to physiological severity for both groups of patients (Craven et al., 1991). Scores on the index showed a weaker relationship with psychological burden of illness which depended in part on treatment mode. Depression scores were positively associated with disease severity in CAPD patients but not in haemodialysis patients, a finding that is consistent with previous studies (e.g., Sacks et al., 1990) that found that severely ill CAPD patients showed poor adjustment. Other research findings of an inconsistent relationship between anxiety and depression and disease severity for the entire group of patients suggest that psychological morbidity is only weakly associated with disease severity in many physically ill populations (Rodin & Voshart, 1986). These findings demonstrate the importance of assessing potential moderator variables in the relationship between illness severity and psychological adjustment (Griffin et al., 1995). Specifically, other factors such as prognosis and prospects for treatment and recovery may have a greater effect on psychological response than disease severity (Griffin et al., 1995). However, the effects of disease severity on these variables should also be explored.

The ESRD-SI is useful for testing psychosocial hypotheses because it assesses disease severity without using psychosocial variables, and without the biases inherent in self-report instruments (Griffin et al., 1995). It has
demonstrable success in providing better control for variability in illness severity, thus minimizing the amount of noise this variable contributes to research results (Craven et al., 1991; Griffin et al., 1995). One possible drawback of the ESRD-SI however is the requirement that it be completed by clinician investigators, thus limiting its research utility. Another limitation of the ESRD-SI is that it is only designed for use with ESRD patients and thus is not necessarily applicable for CRF patients not yet requiring dialysis. As will be seen next, this is not a problem with the use of SORDS.

2.8.3.2 The Severity of Renal Disease Scale (SORDS)

Few instruments exist that address contextual variables such as severity of illness in a valid and reliable way. One such instrument, the Severity of Renal Disease Scale (SORDS), is a research instrument designed to provide a single score reflecting the health status of renal patients, and hence the severity of renal disease. SORDS attempts to measure the severity of the disease with the intent of assessing the influence of illness severity as a suppressor variable (and in some cases, as a moderator variable).

SORDS was originally developed as a tool for research in behavioral medicine, and to assist in the study of the psychological effects of the progression of an illness, such as ESRD. SORDS was conceived as a possible suppressor variable measure which would have the potential to measure how much severity of illness impacted on an individual’s response to treatment for ESRD.
As a research instrument designed to evaluate physical health specific to renal patients, SORDS quantifies the potential impact of diseases most often associated with renal failure by the use of objective symptom criteria (Baltzan et al., unpublished manuscript). It provides a single numerical score which reflects the disease severity (Baltzan et al., unpublished manuscript).

Illness factors included in SORDS were chosen from a comprehensive list of diseases cited both in the literature and by nephrologists as associated with renal failure (Baltzan et al., unpublished manuscript). From these, twenty-two diseases, similarly identified as being those most commonly found in ESRD patients, and classified according to nine major systems, and two symptoms (non-specific nausea and vomiting and rapid weight loss) were chosen. Three specific measures of renal functioning (urine volume, creatinine clearance and glomerular filtration rate) were also included. Some diseases (e.g., colitis, colonic diverticuli, cardiac failure, coronary artery disease, gastritis, ileitis, etc.) were excluded on the basis of a low base rate of occurrence, or the absence of the routine testing required for rating of the scale (Baltzan et al., unpublished manuscript).

Objective criteria for classifying the severity of the disease into four categories (absent, mild, moderate, severe) were based on standard procedures and were developed by medical specialists in the various disease areas (Baltzan et al., unpublished manuscript). For some diseases, two categories (absent vs. present), or three rather than four categories were suggested by the physicians involved. In order to obtain a single score on a
cardinal scale, and equate the severity levels of the various diseases, each severity rating of each disease was scaled on a common underlying dimension of illness severity. The scaling dimension ranged from 0, defined as the absence of a particular disease, up to 100, defined as death. Intermediate and increasing values between 10 and 100 were defined by increasing levels of disability (Baltzan et al., unpublished manuscript).

For each level of each disease or symptom, independent scaling judgements were sought from two panels of judges who were asked to rate the degree of disability associated with the various disease levels (Baltzan et al., unpublished manuscript). One panel consisted of five faculty from the University of Saskatchewan College of Nursing, while the other consisted of five physicians from the Department of Family Medicine, University Hospital (now Royal University Hospital (RUH)), Saskatoon. The disability associated with each severity level of each disease was rated separately by each panelist without discussion with other group members (Baltzan et al., unpublished manuscript). All panel members were provided with sample descriptors of the type and degree of disability to be associated with scale values of 20, 40, 60, and 80 culled from a larger group of disabilities scaled on perceived unpleasantness using hospital patients as judges (Haig et al., 1986). These sample descriptors illustrated functional limitations associated with different levels of disease. The descriptions of functional limitations were not part of the scale, but were instead used to assist panel members to operationalize the
scale levels, hopefully increasing the reliability of ratings given a particular disease level (Baltzan et al., unpublished manuscript).

Each panel member was also provided with a set of assumptions according to which they would scale the level of disability associated with the severity levels of the diseases (Baltzan et al., unpublished manuscript). The assumptions were: (1) that the disease being rated was the only disease present; (2) that the disease state being rated was a chronic condition, as opposed to symptoms of an acute condition; (3) that the person suffering from the disease was between 40 and 45 years of age; and (4) that the disability rating to be assigned to a particular disease severity level should be that associated with the approximate middle of the anticipated range of increasing dysfunction that would result from that severity level (Baltzan et al., unpublished manuscript). Assumption (1) simplified the scaling task even though it is acknowledged that the presence of other diseases would necessarily affect the impact of a given disease (Baltzan et al., unpublished manuscript). Assumption (3) was intended to minimize the effects of confounding factors due to age-related disease impact, while assumption (4) focused attention on assigning a single score representing the disability to be associated with a range of symptoms severity such as "moderate to severe chronic heart disease" (Baltzan et al., unpublished manuscript).

In the final stage of the scaling procedure, each panel of medical personnel as a group was presented with individually scaled values from each panel member for each disease level, as well as the mean and median of the
five individual scalings. A final scale value to be assigned to each disease level was reached by consensus among panel members. The median value was that most often agreed upon; however, on occasion, an extreme value was chosen as most representative of the underlying dimension of disability (Baltzan et al., unpublished manuscript).

In some cases (i.e., ascites, rapid weight loss, and hyperparathyroidism) the panel of nurses were unable to perform the scaling task due to insufficient diagnostic criteria for the severity levels (Baltzan et al., unpublished manuscript). The diagnostic criteria for the diseases/symptoms concerned were changed to reflect this feedback, and these changes were deemed acceptable by the physicians' panel (Baltzan et al., unpublished manuscript). The scaling judgements of the nurses' and physicians' panel were averaged to determine the final scale values rounding to the nearest multiple of 5. A copy of SORDS, together with the final scaling results is appended (Baltzan et al., unpublished manuscript).

Results of reliability analyses were encouraging. The correlation between the final panel scalings ($r = 0.91$, d.f. = 56, $p < 0.00001$) was used to assess the reliability of the scaling process (Baltzan et al., unpublished manuscript). The Spearman-Brown Prophecy Formula was used to determine the reliability of the process of attaching numbers to the various disease levels (e.g., of getting the scale values for the instrument). The Spearman-Brown Prophecy Formula, with a multiplicative factor of 2, yielded a reliability estimate of $r_{kk} = 0.95$, and a standard error of measurement of $s_m = 5.72$ for the resulting
severity scale values. Using the Coefficient Alpha for the scaling judgements, a
reliability estimate of \( r_{xx} = 0.98 \), and a standard error of measurement of \( s_m = 3.62 \) were obtained (Baltzan et al., unpublished manuscript). Thus, using these
values, one can say that the obtained scaled values have a 95% chance of
being replicated within 7.24 to 11.44 points of the original values (Baltzan et al.,
unpublished manuscript). However, the appropriateness of both of these
estimates of reliability based on Coefficient Alpha are possibly biased since the
panel scaling procedure derived values that were not averages of all of the
independently obtained scaling judgements. Further, some data on
diseases/symptoms for the nursing panel was omitted (Baltzan et al.,
unpublished manuscript).

Although the range of scores on SORDS when used to assess disease
severity can theoretically go from zero to 1,615, scores for renal patients are
not likely to span the entire range (Baltzan et al., unpublished manuscript).
Specifically, a score of zero is impossible for a renal patient because the
diagnosis of CRF implies a degree of abnormality on at least some SORDS
dimensions. Similarly, a score of 1,615 can only be obtained if a patient is rated
at the extreme end of all SORDS dimensions. While ESRD patients by
definition are experiencing some organic failure, such extreme scores would
suggest the collapse of virtually all major organ systems, and death.

Preliminary studies of both the reliability and validity of SORDS have
been undertaken (Baltzan et al., unpublished manuscript). The studies of
reliability suggest that SORDS can be reliable instrument (Baltzan et al.,
unpublished manuscript). Two raters independently assessed patients using the SORDS scale using data derived from medical charts. The agreement between the scores of these two raters was low but encouraging (Baltzan et al., unpublished manuscript). The low agreement was determined to be due to discrepant data collection methods between the two raters, differences in levels of familiarity with medical data, and different sources of information (one of the raters was a nurse with personal experience of the patients involved in the study) (Baltzan et al., unpublished manuscript). This result clearly indicated the need for a manual which delineated decisions regarding how to determine the rating given the presence or ambiguity of chart data (Baltzan et al., unpublished manuscript). When procedures were undertaken to correct discrepancies made by the raters, the two ratings correlated .99 with one another. This reliability estimate will require verification in a further study (Baltzan et al., unpublished manuscript).

If scores obtained using SORDS are valid, such scores should reflect a relationship to situations coincident with severity of illness (Baltzan et al., unpublished manuscript). Based on a study using records of patients admitted to University Hospital in the mid-1980's, a significant point-biserial correlation ($r_{pb} = 0.59; p < .0001$) was observed between SORDS scores and death. This correlation was higher than that observed between APACHE (Knaus, 1982), a standardized measure of acute illness and death ($r_{pb} = 0.33; p < .001$). Additionally, patients receiving home dialysis were found to have significantly lower scores on SORDS than patients receiving in-center dialysis. Presumably,
patients are “nominated” for potential home dialysis because of their less severely challenged health state (Baltzan et al., unpublished manuscript). The scaling procedure used to develop SORDS used an underlying scaling dimension which, while defined as increasing disability or dysfunction, could also be considered a threat to life dimension. Indeed, the results of previous studies indicate that SORDS has potential for use as a measure of chronic illness severity for the general population, and not solely for renal patients. Nevertheless, SORDS was designed for use with renal patients. These findings represent preliminary, but very encouraging indications that SORDS is a valid and reliable instrument (Baltzan et al., unpublished manuscript).

In summary, studies of renal populations show inconsistent, sometimes contradictory results. Some of these inconsistencies have been attributed to the heterogeneous nature of renal patient samples, particularly with respect to illness severity. Measures of illness severity such as the SIP and the SF-36, all generic in focus, assess the patient’s reaction and adjustment to his or her illness state, and thus confound physiological psychosocial dimensions. Other generic measures of illness severity as the SII yield ordinal results only, and therefore cannot be used in parametric analysis procedures. The APACHE-III assess illness severity physiologically, but is specifically designed for acute patient groups, potentially limiting the usefulness of the APACHE-III for use with patients suffering from chronic disease.

The only measures specific to end-stage renal failure, assessing severity of illness physiologically are the ESRD-SI and SORDS. This dissertation
assesses the reliability and validity of SORDS using 127 renal patients (predialysis, haemodialysis and continuous ambulatory peritoneal dialysis). SORDS was compared with the ESRD-SI, the BDI-II and a subset of BDI-II items reflecting cognitive features only (BDI-CS) at differing stages of renal disease and time on dialysis. A subset of CAPD patients (n = 22) was used to assess the inter-rater reliability of SORDS and ESRD-SI scores.

Presented next, beginning on the following page, are the specific methods used in the research reported in this dissertation.
3. Methods

This section briefly reviews the psychometric rationale underlying the research methodology. The sample and the data collection procedures, followed by the study hypotheses are then described. Copies of instruments to be used in this project are appended.

As stated in the introduction of this dissertation, the development of SORDS paid close attention to stringent psychometric principles. While preliminary evidence demonstrates that SORDS is face and content valid, and reliably assesses the progression of renal disease severity, it remains necessary to definitively demonstrate reliability and validity. SORDS must be shown to assess variability in illness severity for individuals suffering from ESRD in a consistent manner, and SORDS scores must show anticipated relationships with other variables. A brief overview of the procedures carried out to assess the reliability and validity of SORDS is presented next.

The convergent validity of SORDS was assessed by comparing SORDS scores with scores on the Endstage Renal Disease - Severity Index (ESRD-SI; Craven et al., 1991), a recently developed, psychometrically sound measure of illness severity in renal patients. Divergent validity was assessed by comparing scores on both SORDS and the ESRD-SI with scores on the SF-36 (Ware, 1992), a less disease specific, self-reported general health survey assessing
functional status and general well being. Since the SF-36 indirectly measures quality of life, an inverse relationship between this measure and SORDS would demonstrate that SORDS has utility in research examining quality of life in renal patients.

Validity was also examined by comparing SORDS scores of patient groups at differing stages of renal disease. A measure of depression, the Beck Depression Inventory - 2\textsuperscript{nd} Edition (BDI-II) was concurrently gathered to investigate the usefulness of SORDS in measuring severity of illness as a suppressor variable, or a possible moderator variable. Two scores for the BDI-II were calculated. First the BDI-II was calculated with all 21 items intact. Second, items believed to represent an overlap between the symptoms of uremia and depression (e.g. irritability, decreased appetite, insomnia, decreased energy, fatigue, concentration difficulty) were removed from the BDI-II, and a new total was calculated. The BDI-CS (Cognitive Symptoms) thus served as a measure of depression without the confounding problem of somatic symptoms.

SORDS' reliability was assessed by having a second rater score a subsample of subjects previously rated on SORDS and the ESRD-SI.

The psychometric merit of SORDS was explored by sampling several different populations of renal patients. Samples were identified by the type of treatment received and are described next.
Sample 1: Haemodialysis (HD) Group

SORDS and the ESRD-SI were completed by a nephrologist for n = 51 renal patients currently receiving HD at St. Paul’s Hospital in Saskatoon while they were receiving dialysis. A nurse collected SF-36 and BDI-II data directly from the patients on the same day. Participants filled out the information independently after an explanation of the questionnaire’s content, or had the questionnaire verbally administered. The nurse remained present at all times during this administration to address any questions or concerns from participants. Because some patients in this group may have been on dialysis longer than others, and may therefore have been at different stages of renal disease, the dates at which participants began HD were also be noted.

Sample 2: Continuous Ambulatory Peritoneal Dialysis (CAPD) Group

A nephrologist collected SORDS and ESRD-SI scores from approximately n = 50 CAPD clinic patients. A nurse administered the BDI-II to these patients while they were present in the clinic. Given the short time the patients were in the clinic, SF-36 was not gathered. It was felt that BDI-II data was more essential.

Sample 3: Pre-dialysis (Pre-D) Group

In a similar fashion, SF-36, BDI-II, SORDS and ESRD-SI scores were collected from approximately n = 16 patients who had been diagnosed with
renal dysfunction, but who did not require dialysis. This sample will be referred to as the “Pre-dialysis” sample (Pre-D).

Ethical approval from the University of Saskatchewan Ethics Committee was obtained prior to gathering data on any patients to be included in the study. Consent forms were provided outlining the study purpose. Copies of the consent forms are appended.

Dr. George Pylypchuk, a local nephrologist, was instrumental in securing the cooperation of the St. Paul's Hospital Renal Unit for this research, and identifying research assistants for the study. He has also collaborated with his colleague, Dr. Judy Klassen, another nephrologist to contribute to the inter-rater reliability assessment of SORDS. Sample size for all study groups was limited by the time available to the data collectors. However, 100% of those patients invited to participate agreed to do so.

The process of data collection took place in Saskatoon, and is described as follows. Nephrologists were familiarized with SORDS and the ESRD-SI but remained blind to the study hypotheses. They recruited all study participants, and completed SORDS and the ESRD-SI for each patient from these patients’ existing medical files. Similarly, two nurses trained on the SF-36 and BDI-II and also blind to the study hypotheses collected data from patients for three of the participant groups, namely the HD, CAPD and Pre-D groups. The nurses administered the SF-36, and the BDI-II to the HD and Pre-D patients and the BDI-II only to the CAPD patients. They were instructed to remain alert for possible comprehension, language or hearing difficulties that may be displayed
through facial expression, or obvious hesitation when answering items. Permission of patients to use this data was sought in writing.

Prior to data collection, Dr. Pylypchuk reviewed SORDS, and suggested that hyperparathyroidism be assessed using hormone levels which he provided. This modification was included in the data collection form used in this study. As data collection progressed various other suggestions for improvement were made by Dr. Pylypchuk. These would have substantially altered the structure of the scale and for that reason, were not incorporated into the present version of SORDS. The changes proposed by Dr. Pylypchuk included the deletion of redundant items such as glomerular filtration rate and urine volume, and the addition of items specific to the evaluation of dialysis adequacy. As will be seen in the results section, however, it was possible to examine the impact of excluding certain items from SORDS in the data analyses. Suggestions for further improvement and possible revisions of SORDS to be investigated at a later date are discussed in greater depth in the section entitled Future Research.

The following study hypotheses were investigated:

**Research Hypothesis 1:**

Scores on SORDS were expected to correlate highly with scores on the ESRD-SI. Since high scores on SORDS and the ESRD-SI are associated with increasing severity of illness, scores on both instruments should be significantly
lower for patients with renal dysfunction not yet requiring dialysis (the Pre-D group) than for those patients in later stages of ESRD, and receiving dialysis.

**Research Hypothesis 2:**

Studies indicate that survival decreases rapidly with advancing age at time of renal failure, from 95.1% among non-diabetic patients 15 to 24 years to 52.5% for patients over the age of 85 (Eggers, 1990). Although there is no direct evidence of increased severity of disease among this category of patients, the extension of dialysis therapy to older patients is suggestive that additional, unmeasured changes in severity may account for these mortality changes. Based on these findings, it was hypothesized that older, and presumably sicker patients would have higher scores on both SORDS and the ESRD-SI.

**Research Hypothesis 3:**

SORDS and the ESRD-SI scores were expected to be negatively correlated with SF-36 composite T-scores, specifically, the Physical Health (PHC-T), Mental Health (MHC-T) and Global Health Composite (GHC-T). Since higher SF-36 scores represent better overall health status and well-being, there should be an inverse relationship between progressive renal failure and quality of life. As such, increasing severity of illness as reflected by high SORDS scores was expected to be associated with diminished functional status and diminished general well-being as reflected by low SF-36 scores. It was anticipated that correlations would be significant, but lower than those between
SORDS and the ESRD-SI because scores on the SF-36 reflect patients' attitude and adjustment to their physical and mental health conditions rather than the purely physiological aspects of renal disease.

**Research Hypothesis 4:**

The potential utility of SORDS as a control variable in psychosocial research was investigated by examining scores on the Beck Depression Inventory-II [BDI-II] from three groups of patients. Subsequent exploratory analyses controlled for disease severity via SORDS scores to discover what relationships emerged. These groups include samples 1, 2, and 3 previously described.

It was anticipated that those patients with less control over their treatment (e.g., in-center HD) would be less depressed with increasing illness severity. Conversely, it was expected that patients with greater control over their treatment (e.g., CAPD patients) would have higher scores on the depression scales with increasing illness severity. Patients not yet on dialysis likely represent those with the least severely compromised health status. It was expected that this group will be the least depressed of all renal patient groups.

**Research Hypothesis 5:**

Given the encouraging results of previous reliability studies, it was expected that reliability estimates for SORDS would be high. To assess SORDS reliability, a subsample (n = 22) of randomly selected medical charts from this group was used to generate SORDS and ESRD-SI scores by a
second, independent rater. Both raters were nephrologists, and familiar with the items and the physiological nature of the data required to rate both SORDS and the ESRD-SI. Of the 22 patients, only eight were scored by the two raters at roughly the same time. Fourteen (14) patients in sample 2 were scored retrospectively from chart data approximately six months apart. In order to ensure that ratings were not affected by the passage of time, the second rater was instructed to rate chart data that was obtained within the same period the first rater collected the data. It was decided that in the interests of time she would also be instructed to disregard certain items that were highly susceptible to variation across time and were rated according to objective, laboratory findings (e.g., parathyroid hormone levels). These were also least likely to be subject to the vicissitudes of clinical judgement, and as such, the ratings given by the first nephrologists were accepted as valid for both assessments.

All data analyses (correlations, t-tests, ANOVA's, etc.) Were carried out using SPSS for Windows, version 10.
4. Results

The following section will present analyses of data gathered at St. Paul's Hospital Renal Unit in Saskatoon, Saskatchewan by a staff nephrologist and a renal unit nurse. Also included in the analyses are data gathered at the Saskatoon private practice offices of the same nephrologist.

The samples included patients from haemodialysis (HD) and continuous ambulatory peritoneal dialysis (CAPD) units at St. Paul's hospital, as well as patients who had been diagnosed with renal dysfunction but who did not yet require dialysis (Pre-D) from a private clinic. The HD and Pre-D patients were administered the BDI-II and the SF-36, while their SORDS and ESRD-SI scores were obtained from chart information. The CAPD patients were administered the BDI-II only, with SORDS and ESRD-SI scores also obtained from chart data. A subsample of the CAPD patients were used for an assessment of SORDS and ESRD-SI reliability.

Following a description of the samples, the results will be presented in the order the research hypotheses appear in the methods section. Demographic data will be presented by treatment group. Results from the validity and reliability analyses will be described with reference to the hypotheses explored. Tables will be used to summarize relevant statistics.
4.1 Demographic Characteristics of Study Samples

Of the 115 HD patients receiving dialysis over the period of data collection, 51 patients participated in the study. One patient found the BDI-II very distressing, and asked to be excused from completing the assessment, and one patient did not complete the BDI-II for unspecified reasons. The average age of the HD patients was 58.06 years, with a standard deviation of 16.99.

For the CAPD group, of the 70 patients attending the outpatient peritoneal dialysis clinic at St. Paul's Hospital over the period of data collection, 60 patients participated in the study. Of these, 50 patients completed BDI-II assessments during the initial period of data collection. Two patients did not complete the BDI-II, one for unspecified reasons, and another because the questions were felt by the patient to be distressingly personal. Eight CAPD patients joined the study some time after the BDI-II data had been collected, and as a result, these eight patients have scores for SORDS and the ESRD-SI only. These patients are not included in analyses examining the relationship between SORDS and such psychological data.

The participating nephrologist was provided with the list of CAPD patients for whom BDI-II data was available, and completed SORDS and the ESRD-SI using chart reviews for these patients. Due to time constraints, only 44 patients' medical files were scored on SORDS and the ESRD-SI. SORDS and ESRD-SI data from twenty-two of the CAPD patients was used for
purposes of assessing reliability and will be summarized in the section dealing with reliability analyses.

The average age of the CAPD patients was 57.63 with a standard deviation of 17.50. Sixteen (16) predialysis patients from a local nephrology private practice clinic were invited and agreed to participate in the study. The average age of this sample was 64.63, with a standard deviation of 16.97.

This demographic information demonstrates the heterogeneity of the sample. The data sample contains 127 cases. Of these, 56 are females and 71 are males. The average age of this sample is 58.69 years with a standard deviation of 17.25.

A summary of the age statistics can be seen in Table 4.1.

**Table 4.1** Age of subjects.

<table>
<thead>
<tr>
<th>Renal Disease Groups</th>
<th>HD</th>
<th>CAPD</th>
<th>Pre-D</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (n, SD)</td>
<td>Range</td>
<td>Mean (n, SD)</td>
</tr>
<tr>
<td>Male</td>
<td>56.65 (26, 4.8)</td>
<td>28 to 84</td>
<td>61.74 (38, 3.9)</td>
</tr>
<tr>
<td>Female</td>
<td>59.52 (25, 19.2)</td>
<td>21 to 81</td>
<td>50.55 (22, 20.8)</td>
</tr>
<tr>
<td>Total</td>
<td>58.06 (51, 17.0)</td>
<td>21 to 84</td>
<td>57.63 (60, 17.5)</td>
</tr>
</tbody>
</table>

The HD and CAPD samples are comprised of a wide range of treatment duration (from one month to eleven years) as shown in Table 4.2. Note that the predialysis group is not included in Table 4.2 since the patients in this group are by definition not yet receiving dialysis treatment for renal dysfunction.
Table 4.2 Duration on dialysis in months, HD and CAPD groups.

<table>
<thead>
<tr>
<th>Renal Disease Groups</th>
<th>HD</th>
<th>CAPD</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Range</td>
</tr>
<tr>
<td>Male</td>
<td>32.69 (30.71)</td>
<td>2 to 123</td>
</tr>
<tr>
<td>Female</td>
<td>39.08 (34.41)</td>
<td>6 to 135</td>
</tr>
<tr>
<td>Total</td>
<td>35.82 (32.41)</td>
<td>2 to 135</td>
</tr>
</tbody>
</table>

4.2 Research Hypothesis 1 (Comparison of SORDS and the ESRD-SI)

Mean scores on SORDS and the ESRD-SI for samples 1 to 3 are shown in Table 4.3, together with the standard deviations and ranges for the three samples.

Table 4.3 SORDS and the ESRD-SI average scores for samples 1, 2 and 3.

<table>
<thead>
<tr>
<th>Renal Disease Groups</th>
<th>HD (n = 51)</th>
<th>CAPD (n = 60)</th>
<th>Pre-D (n = 16)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Range</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>ESRD-SI</td>
<td>7.64 (7.6)</td>
<td>0 to 26</td>
<td>9.38 (7.9)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>8.00 (5.8)</td>
</tr>
<tr>
<td>SORDS</td>
<td>308.33 (64.4)</td>
<td>75 to</td>
<td>301.44 (40.4)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>95.56 (59.8)</td>
</tr>
</tbody>
</table>

It was hypothesized that SORDS would correlate highly with scores on the ESRD-SI, and further, that since high scores on SORDS and the ESRD-SI are associated with increasing severity of illness, scores on both instruments should be significantly lower for patients with renal dysfunction not yet requiring
dialysis than for those patients in later stages of ESRD, and currently receiving dialysis.

As a first approach to investigating this hypothesis, Pearson correlations were computed between SORDS and the ESRD-SI. It should be noted that SORDS includes a renal function dimension which the ESRD-SI does not. Therefore, an additional correlational analysis was carried out using adjusted SORDS scores (called SORDS-K) removing renal function items to put the two instruments on a more equal footing. The results of these analyses are in Table 4.4.

**Table 4.4** Correlations between SORDS, SORDS-K and ESRD-SI for various renal patient groups.

<table>
<thead>
<tr>
<th>Variables</th>
<th>Renal Groups</th>
<th>n = 51</th>
<th>n = 52</th>
<th>n = 16</th>
<th>n = 103</th>
<th>n = 119</th>
</tr>
</thead>
<tbody>
<tr>
<td>SORDS vs ESRD-SI</td>
<td>HD (1)</td>
<td>.63**</td>
<td>.59**</td>
<td>.27</td>
<td>.62**</td>
<td>.40**</td>
</tr>
<tr>
<td>SORDS-K vs ESRD-SI</td>
<td>CAPD (2)</td>
<td>.72**</td>
<td>.59**</td>
<td>.60**</td>
<td>.68**</td>
<td>.67**</td>
</tr>
</tbody>
</table>

** Correlations significant at the .01 level.

Correlations between SORDS and the ESRD-SI were moderately high when all renal patient groups were combined. However, there are two possible attenuating factors in these correlations both of which concern discrepancies in scale construction and content coverage between the two severity measures. One obvious discrepancy is the presence of a renal dysfunction dimension on
SORDS but not the ESRD-SI. However, even when the renal sufficiency
dimension is eliminated from SORDS (creating SORDS-K scores) the
relationship between the ESRD-SI and scores across the remaining SORDS
items is essentially the same. When the individual samples were separately
analysed, some fluctuation in the correlation values was observed, but none of
the correlations differed significantly (except one correlation for the Pre-D
group).

A comparison of items covered by both SORDS and the ESRD-SI
reveals another important difference. Apart from the addition of a renal
dysfunction dimension, SORDS covers each individual disease category more
comprehensively than does the ESRD-SI. This difference may also explain
differences in sensitivity between the two measures as discussed later in this
chapter. Nevertheless, these correlational results lead to a conclusion that a
moderately high relationship exists between SORDS (and SORDS-K) and the
ESRD-SI, providing supportive evidence for convergent validity. This last point
will be discussed more fully in the next chapter.

Pearson correlational analyses examine potential linear relationships
between variables such as SORDS and the ESRD-SI. An additional analysis
examining the potential validity of SORDS compared the mean scores on these
instruments for the three patient groups (HD, CAPD and Pre-D).

A one-way analysis of variance (ANOVA) was conducted for SORDS
and ESRD-SI data reported in Table 4.3. Mean SORDS scores for the three

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samples were significantly different ($F = 101.41; \text{df} = 2, 116; p < 0.0005$), but
the mean ESRD-SI scores did not differ significantly ($F = .38; \text{df} = 2, 116; \text{N.S.}$).

Analogous to the earlier discussion in the correlational analysis results, a
possible criticism of a comparison of SORDS scores for these three samples is
that the differences among groups may be solely attributable to differences in
kidney function. In other words, in analyses comparing SORDS scores between
dialysis and predialysis groups, the presence of scores reflecting kidney
dysfunction (e.g., creatinine clearance, gfr, and urine volume) could bias, or
inflate scores on the severity measures for the dialysis groups. To address this
issue, a one-way ANOVA was also carried out comparing the average SORDS-
K scores for all three renal patient samples. Mean SORDS-K scores for the
three samples were found to be marginally significantly different ($F = 2.994; \text{df}
= 2, 116; p < 0.054$).

A summary of the ANOVA results, and subsequent pair-wise
comparisons using the Student-Newman-Keuls procedure are shown in Table
4.5 on the following page.
Table 4.5  ANOVA and pair-wise comparison results: Mean SORDS, SORDS-K and ESRD-SI scores for renal patient groups.

<table>
<thead>
<tr>
<th>Variable</th>
<th>F-ratio</th>
<th>p</th>
<th>Student-Newman-Keuls: α = .05</th>
</tr>
</thead>
<tbody>
<tr>
<td>ESRD-SI total</td>
<td>0.379</td>
<td>N.S.</td>
<td>Pre-D</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>8</td>
</tr>
<tr>
<td>SORDS total</td>
<td>101.411</td>
<td>&lt;.0005</td>
<td>Pre-D</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>96.56</td>
</tr>
<tr>
<td>SORDS-K</td>
<td>2.994</td>
<td>0.054</td>
<td>Pre-D</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>44.69</td>
</tr>
</tbody>
</table>

Note 1. All F-ratios have d.f. = 2, 116.
Note 2. Means connected by a common underline do not differ significantly.

The results presented in Table 4.5 demonstrate that SORDS, even when renal sufficiency dimensions items are eliminated, does significantly discriminate between patients requiring dialysis and patients experiencing chronic renal disease but not yet requiring dialysis.

The scatterplots shown in Figures 4.1 and 4.2 on the following pages support the above conclusions and favor SORDS as the instrument more sensitive to extremes in illness severity in renal patients. This advantage is likely due to wider content coverage and wider range of illness severity scalings on SORDS as compared to the ESRD-SI.

The data in Figure 4.1 demonstrate the relationship between SORDS and the ESRD-SI for the CAPD and HD groups only. This figure demonstrates that the ESRD-SI is not as sensitive to concomitant diseases associated with renal disease as is SORDS. For example, ten people have a range of SORDS
scores from approximately 180 to 360. These same ten people have ESRD-SI scores of zero. The outliers, when deleted have little effect upon the overall correlation. The correlation for the Figure 4.1 data is $r = .615$: the deletion of the high outlier decreases the correlation to .60 while deletion of the low outlier raises correlation to .68.

**Figure 4.1** SORDS vs ESRD-SI, HD and CAPD groups combined

Figure 4.2, presented on the following page, represents all three patient samples (CAPD, HD, and PRE-D). Here the differences between SORDS and the ESRD-SI are more pronounced. The cluster of scores to the left represent
the PRE-D group. ESRD-SI scores for the Pre-D group remain roughly equivalent to those obtained by the dialysis groups presumably containing more seriously ill patients, thereby failing to differentiate between extremes of renal illness severity. Because ESRD-SI scores do not extend below zero, the range of possible values is restricted, and a truncated correlation results (e.g., \( r = 0.400 \)). More simply put, the ESRD-SI suffers from too low a ceiling and too high a floor, a probable artifact of the less comprehensive content coverage of the ESRD-SI.

**Figure 4.2** SORDS vs ESRD-SI, all renal patient groups
In contrast, SORDS scores support the commonly held clinical differentiation of ESRD from CRF, namely that ESRD patients suffer from more serious renal failure and are referred for dialysis literally to keep them alive while CRF patients show signs of renal dysfunction but are able to produce and excrete urine without dialysis. SORDS scores show distinct, statistically significant differences between treatment and non-treatment groups.

The scatterplots support the ANOVA results previously presented in Table 4.5 which showed significant differences between pre-dialysis and dialysis groups on SORDS but no differences as measured by the ESRD-SI. It will be recalled that the ESRD-SI measures illness severity in dialysis patients only as evidenced by the absence of renal function items and the inclusion of an ‘access & dialysis events’ item (hence the name “End-Stage Renal Disease - Severity Index”).

Figures 4.1 and 4.2 also demonstrate visually the greater capacity of SORDS to measure early symptoms of renal failure. An additional point in favor of SORDS is that scaling procedures used in its early development were such that scores on individual items more accurately reflect the medical community’s view of the impact of individual disease on a person’s life. These analysis results provide strong evidence supporting the validity of SORDS.

4.3 Research Hypothesis 2 (Comparison of Age with Scores on SORDS and the ESRD-SI)

It was also hypothesized that older patients will have lower scores on both SORDS and the ESRD-SI. Correlational analyses revealed that age bears
no significant relationship to scores on either SORDS or ESRD-SI scores in any of the dialysis groups in this sample, an unsurprising result given the very wide range of age in all groups. The correlations ranged from $r = -0.05$ to $r = 0.41$, but this last value was based on the $n = 16$ pre-dialysis group and was non-significant. Most of the correlations were less than 0.20. Subsequent ANOVA analyses, based on quartile groupings of SORDS and ESRD-SI scores (described in more detail later) revealed no significant relationships between average patient age and severity of renal disease.

4.4 Research Hypothesis 3 (Comparison of SORDS, ESRD-SI and SF-36 Scales)

Divergent validity was assessed by comparing scores on both SORDS and the ESRD-SI with scores on the SF-36 (Ware, 1992), a less disease specific, self-reported general health survey assessing functional status and well being in general.

SORDS and the ESRD-SI scores were expected to be negatively correlated with SF-36 composite T-scores, specifically, the Physical Health (PHC), Mental Health (MHC) and Global Health Composite (GHC) scores.

The results presented below were obtained from the HD and Pre-D samples as CAPD patients were not administered the SF-36. Analyses were performed separately, then with combined samples. These analyses are presented in Table 4.6 on the following page.
Table 4.6  Correlations between SORDS, SORDS-K and SF-36 scores for renal patient groups.

<table>
<thead>
<tr>
<th>Variables:</th>
<th>Renal Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Renal Scale</td>
<td>SF-36 scale</td>
</tr>
<tr>
<td>SORDS</td>
<td>MHC</td>
</tr>
<tr>
<td></td>
<td>PHC</td>
</tr>
<tr>
<td></td>
<td>GHC</td>
</tr>
<tr>
<td>SORDS-K</td>
<td>MHC</td>
</tr>
<tr>
<td></td>
<td>PHC</td>
</tr>
<tr>
<td></td>
<td>GHC</td>
</tr>
<tr>
<td>ESRD-SI</td>
<td>MHC</td>
</tr>
<tr>
<td></td>
<td>PHC</td>
</tr>
<tr>
<td></td>
<td>GHC</td>
</tr>
</tbody>
</table>

*  Correlations significant at the .05 level.
** Correlations significant at the .01 level.

There were no significant correlations among SORDS, SORDS-K and SF-36 scores for the Pre-D sample, a not unanticipated result given the sample size (n = 16). Weak but significant correlations were observed between SORDS and scores on the PHC and GHC for the HD sample but not when samples were combined. There were no significant correlations found between SORDS scores and scores on the MHC. When items measuring kidney dysfunction were eliminated, the results were similar except for the presence of a significant correlation between scores on SORDS-K and scores on the PHC for combined groups.
A weak but significant relationship was also observed between PHC scores and scores on the ESRD-SI for the HD sample and between the ESRD-SI and the PHC and GHC scores for the combined samples. Scores between the ESRD-SI and the MHC scale were not correlated.

These results indicate that higher scores on SORDS as well as the ESRD-SI were marginally related to lower self-perception of physical functioning as assessed by the SF-36 composite scores. Correlations between the SF-36 and measures of renal disease severity provide support for the divergent validity of both SORDS and the ESRD-SI. Specifically, measures such as the SF-36, while reflecting variation in self-perceived health status, also reflect the individual’s level of adjustment to their condition. Thus, lower correlations between the SF-36 scales and measures of renal disease severity are to be expected as SORDS and the ESRD-SI are objective measures of physical health status that are independent of psychosocial influences.

4.5 Research Hypothesis 4 (Utility of Severity of Illness Measures as Control Variables in Psychosocial Research): Correlation Analyses

Pearson correlations were computed between the BDI-II, the BDI-CS and the three illness severity measures (SORDS, ESRD-SI and the SF-36). The BDI-CS scores were computed by omitting those BDI-II items with a significant somatic component. The results of these analyses for various combinations of the clinical samples are presented in Table 4.7 on the following page.
Table 4.7  Correlations between severity of illness measures and measures of depression.

<table>
<thead>
<tr>
<th>Variables:</th>
<th>Renal Groups 1.2.</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>HD (1)</td>
<td>CAPD (2)</td>
<td>Pre-D (3)</td>
<td>1+2</td>
<td>1+2+3 3.</td>
</tr>
<tr>
<td>SORDS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BDI-II</td>
<td>.33*</td>
<td>-.011</td>
<td>-.34</td>
<td>.016</td>
<td>.012</td>
</tr>
<tr>
<td>BDI-CS</td>
<td>.32*</td>
<td>-.014</td>
<td>-.38</td>
<td>.015</td>
<td>.014</td>
</tr>
<tr>
<td>SORDS-K</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BDI-II</td>
<td>.32*</td>
<td>-.011</td>
<td>-.14</td>
<td>.015</td>
<td>.014</td>
</tr>
<tr>
<td>BDI-CS</td>
<td>.31*</td>
<td>-.014</td>
<td>-.16</td>
<td>.012</td>
<td>.012</td>
</tr>
<tr>
<td>ESRD-SI</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BDI-II</td>
<td>.32*</td>
<td>-.002</td>
<td>-.05</td>
<td>.19*</td>
<td>.18*</td>
</tr>
<tr>
<td>BDI-CS</td>
<td>.31*</td>
<td>.001</td>
<td>-.09</td>
<td>.19*</td>
<td>.18*</td>
</tr>
<tr>
<td>MHC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BDI-II</td>
<td>-.72**</td>
<td>N/A</td>
<td>-.78**</td>
<td>N/A</td>
<td>-.72**</td>
</tr>
<tr>
<td>BDI-CS</td>
<td>-.72**</td>
<td>N/A</td>
<td>-.76**</td>
<td>N/A</td>
<td>-.71**</td>
</tr>
<tr>
<td>PHC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BDI-II</td>
<td>-.69**</td>
<td>N/A</td>
<td>-.51*</td>
<td>N/A</td>
<td>-.64**</td>
</tr>
<tr>
<td>BDI-CS</td>
<td>-.64**</td>
<td>N/A</td>
<td>-.46*</td>
<td>N/A</td>
<td>-.59**</td>
</tr>
<tr>
<td>GHC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BDI-II</td>
<td>-.79**</td>
<td>N/A</td>
<td>-.76**</td>
<td>N/A</td>
<td>-.72**</td>
</tr>
<tr>
<td>BDI-CS</td>
<td>-.76**</td>
<td>N/A</td>
<td>-.72**</td>
<td>N/A</td>
<td>-.74**</td>
</tr>
</tbody>
</table>

Note 1. Number of subjects in the renal groups are: HD, 51 subjects; CAPD, 50 subjects; Pre-D, 16 subjects.
Note 2. SF-36 scores only available for HD and Pre-D subjects.
Note 3. Correlations with SF-36 exclude CAPD subjects.

* Correlations significant at the .05 level.
** Correlations significant at the .01 level.

Generally, the results presented in Table 4.7 show weak to non-significant correlations between the renal disease severity measures and depression as assessed by the BDI-II and BDI-CS for all combinations of renal disease groups. Additionally, scores on the SF-36 scales show relatively strong correlations with the BDI-II and BDI-CS. The relationships examined by these
correlations are next examined by ANOVA analyses by grouping patients into quartiles based in severity of illness scores.

4.6 Research Hypothesis 4 (Utility of Severity of Illness Measures as Control Variables in Psychosocial Research): ANOVA Analyses

It must be remembered that correlational analyses reported in section 4.5 assess the extent of linear relationships between the measures in question. For this reason, additional analyses were conducted examining these relationships by dividing the subjects within renal disease groups into quartiles based on SORDS and ESRD-SI scores. Subjects with lowest scores comprised the 1st quartile, and subjects with highest scores comprised the 4th quartile.

The quartile analyses did not involve the Pre-D subjects because of the wide discrepancy in SORDS and ESRD-SI scores for this group compared to the dialysis samples, and because of the relatively small number of Pre-D subjects. The exclusion of Pre-D subjects also led to the quartile analyses being carried out using SORDS and ESRD-SI scores only (SORDS-K was used to minimize possible bias in analyses examining differences between the Pre-D group and the dialysis samples).

The quartile analyses involved 2 x 4 factorial design ANOVA’s with type of dialysis (HD or CAPD) as one design factor, and severity of renal disease as reflected by quartile grouping as the other design factor. The dependent variables in these analyses were BDI-II and BDI-CS scores. The results of these analyses will be presented for each dependent variable separately, with the initial ANOVA table followed by a simple main effects ANOVA table. This

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presentation format is used because of what will be seen to be a significant interaction between dialysis group and level of renal disease severity as each impact upon self-reported levels of depression.

4.6.1 ANOVA analyses involving BDI-II scores

Table 4.8 shows mean BDI-II scores for the two dialysis groups by level of renal disease severity as assessed by SORDS quartile standing.

**Table 4.8** Mean BDI-II scores for HD and CAPD patients classified by SORDS quartile standings.

<table>
<thead>
<tr>
<th>Dialysis Group</th>
<th>SORDS Quartile</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1st</td>
<td>2nd</td>
<td>3rd</td>
<td>4th</td>
<td>Total</td>
</tr>
<tr>
<td>HD</td>
<td>6.5 (14)</td>
<td>11.9 (14)</td>
<td>17.0 (10)</td>
<td>16.4 (11)</td>
<td>12.4 (49)</td>
</tr>
<tr>
<td>CAPD</td>
<td>23.3 (9)</td>
<td>8.4 (12)</td>
<td>10.8 (12)</td>
<td>12.9 (9)</td>
<td>13.2 (42)</td>
</tr>
<tr>
<td>Total</td>
<td>13.1 (23)</td>
<td>10.3 (26)</td>
<td>13.6 (22)</td>
<td>14.8 (20)</td>
<td>12.8 (91)</td>
</tr>
</tbody>
</table>

**Note 1.** Mean BDI-II scores are followed by the number of patients in the particular cell shown in parentheses.

The initial 2-way ANOVA of the means shown in Table 4.8 is presented in Table 4.9. Table 4.10 shows the results of a simple main effects ANOVA, while Table 4.11 shows the pair-wise-comparisons of significant results from Table 4.10 using Student-Newman-Keuls.
Table 4.9  2-way ANOVA of BDI-II scores for HD and CAPD patients classified by SORDS quartile standings.

<table>
<thead>
<tr>
<th>Source</th>
<th>d.f.</th>
<th>F-ratio</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Renal Group</td>
<td>1</td>
<td>&lt; 1</td>
<td>N.S.</td>
</tr>
<tr>
<td>Severity Level</td>
<td>3</td>
<td>1.04</td>
<td>N.S.</td>
</tr>
<tr>
<td>Group by Severity</td>
<td>3</td>
<td>5.59</td>
<td>0.002</td>
</tr>
<tr>
<td>Error</td>
<td>83</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>91</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Given the significant interaction between dialysis group and severity level, a simple main effects ANOVA was then carried out. It will be noted in Table 4.9 that no significant main effects were found.

Table 4.10 Simple main effects ANOVA for means reported in Table 4.8. ¹.

<table>
<thead>
<tr>
<th>Source</th>
<th>d.f.</th>
<th>F-ratio</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>B at a₁</td>
<td>3</td>
<td>2.59</td>
<td>N.S. (&lt; .10)</td>
</tr>
<tr>
<td>B at a₂</td>
<td>3</td>
<td>3.76</td>
<td>&lt; .025</td>
</tr>
<tr>
<td>A at b₁</td>
<td>1</td>
<td>13.77</td>
<td>&lt; .005</td>
</tr>
<tr>
<td>A at b₂</td>
<td>1</td>
<td>&lt; 1</td>
<td>N.S.</td>
</tr>
<tr>
<td>A at b₃</td>
<td>1</td>
<td>1.89</td>
<td>N.S.</td>
</tr>
<tr>
<td>A at b₄</td>
<td>1</td>
<td>&lt; 1</td>
<td>N.S.</td>
</tr>
<tr>
<td>Error</td>
<td>83</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note ¹. Renal group = A, with a₁ = HD and a₂ = CAPD; SORDS severity level = B, with b₁ = 1ˢᵗ quartile, b₂ = 2ⁿᵈ quartile, b₃ = 3ʳᵈ quartile and b₄ = 4ᵗʰ quartile.

From Table 4.10, it can be seen that a significant difference in mean BDI-II scores exists across the SORDS quartile groups for CAPD patients, i.e.,
the B at a 2 analysis (F = 3.76; d.f. = 3.76; p < .025). The mean BDI-II scores for the SORDS quartile groups within the HD patient group did not differ significantly at the α = .05 level, but did show a marginally significant difference at the α = .10 level. Finally, mean BDI-II scores for HD and CAPD dialysis patient groups differed significantly for only those patients at the lowest level of severity of renal disease as assessed by SORDS (i.e., the 1st quartile group only). Table 4.11 shows pairwise comparison analyses examining the specific differences for each dialysis patient group.

Table 4.11 Student-Newman-Keuls analyses of BDI-II means for SORDS severity groups.

<table>
<thead>
<tr>
<th>SORDS Quartile Group</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>BDI-II Means for HD patients</td>
<td>6.5</td>
<td>11.9</td>
<td>16.4</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Student-Newman-Keuls: α = .10</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SORDS Quartile Group</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>BDI-II Means for HD patients</td>
<td>6.5</td>
<td>11.9</td>
<td>16.4</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Student-Newman-Keuls: α = .05</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SORDS Quartile Group</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>BDI-II Means for CAPD patients</td>
<td>8.4</td>
<td>10.8</td>
<td>12.9</td>
<td>23.3</td>
</tr>
</tbody>
</table>

Note 1. Means connected by a common underline do not differ significantly.

The results presented above in Table 4.11 show where significant differences exist between BDI-II means for SORDS severity groups within each dialysis group. It will be remembered that the simple main effects ANOVA reported in Table 4.10 also showed a significant difference in the mean BDI-II
scores for the lowest severity level on SORDS (i.e., 1st quartile) across the two dialysis groups. This result is simply understood by referring back to Table 4.8. The mean BDI-II score for the 1st quartile severity group of HD patients was 6.5. The mean BDI-II score for the 1st quartile severity group of CAPD patients was 23.3. These two means differ significantly.

The results presented above are perhaps best understood by the data presented on the following page in Figure 4.3.

**Figure 4.3** Mean BDI-II scores for HD and CAPD patients classified by SORDS quartile standings.

![Graph showing BDI-II scores across quartiles for HD and CAPD patients.]

Figure 4.3 illustrates the interactive relationship between depression, severity of illness and type of dialysis treatment. Within the lowest quartile level of severity, patients receiving continuous ambulatory peritoneal dialysis are
significantly more depressed than patients receiving in-hospital haemodialysis at the same severity level. While there are slight differences between the dialysis groups at other levels of severity, the disparity is most pronounced for those patients obtaining the lowest SORDS scores. The scores obtained by the CAPD group places these patients within the moderate range of depression as assessed by the BDI-II. These results have important implications for the psychosocial assessment and treatment of renal patients and their families. This will be discussed in more detail later.

4.6.2 ANOVA analyses involving BDI-CS scores

These analyses were repeated for the BDI-CS to eliminate the possibility of a physical confound. The results of analyses examining BDI-CS scores are presented in Tables 4.12 to 4.15.

Table 4.12  Mean BDI-CS scores for HD and CAPD patients classified by SORDS quartile standings. 1.

<table>
<thead>
<tr>
<th>Dialysis Group</th>
<th>1st</th>
<th>2nd</th>
<th>3rd</th>
<th>4th</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>HD</td>
<td>3.4 (14)</td>
<td>7.9 (14)</td>
<td>10.8 (10)</td>
<td>10.4 (11)</td>
<td>7.8 (49)</td>
</tr>
<tr>
<td>CAPD</td>
<td>16.9 (9)</td>
<td>4.9 (12)</td>
<td>5.8 (12)</td>
<td>8.0 (9)</td>
<td>8.4 (42)</td>
</tr>
<tr>
<td>Total</td>
<td>8.6 (23)</td>
<td>6.5 (26)</td>
<td>8.1 (22)</td>
<td>9.3 (20)</td>
<td>8.0 (91)</td>
</tr>
</tbody>
</table>

Note 1. Mean BDI-CS scores are followed by the number of patients in the particular cell shown in parentheses.

The initial 2-way ANOVA of the means shown in Table 4.12 is presented in Table 4.13. Table 4.14 shows the results of a simple main effects ANOVA, while Table 4.15 shows the pairwise comparisons of significant results from Table 4.14 using Student-Newman-Keuls.
Table 4.13 2-way ANOVA of BDI-CS scores for HD and CAPD patients classified by SORDS quartile standings.  

<table>
<thead>
<tr>
<th>Source</th>
<th>d.f.</th>
<th>F-ratio</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Renal Group</td>
<td>1</td>
<td>&lt; 1</td>
<td>N.S.</td>
</tr>
<tr>
<td>Severity Level</td>
<td>3</td>
<td>&lt;1</td>
<td>N.S.</td>
</tr>
<tr>
<td>Group by Severity</td>
<td>3</td>
<td>5.5</td>
<td>0.002</td>
</tr>
<tr>
<td>Error</td>
<td>83</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>91</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Given the significant interaction between dialysis group and severity level, and simple main effects ANOVA was then carried out. (It will be noted in Table 4.13 that no significant main effects were found.) The simple main effects ANOVA results are presented next in Table 4.14.

Table 4.14 Simple main effects ANOVA for means reported in Table 4.12.  

<table>
<thead>
<tr>
<th>Source</th>
<th>d.f.</th>
<th>F-ratio</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>B at a₁</td>
<td>3</td>
<td>1.99</td>
<td>N.S.</td>
</tr>
<tr>
<td>B at a₂</td>
<td>3</td>
<td>3.97</td>
<td>&lt; .025</td>
</tr>
<tr>
<td>A at b₁</td>
<td>1</td>
<td>13.65</td>
<td>&lt; .005</td>
</tr>
<tr>
<td>A at b₂</td>
<td>1</td>
<td>&lt; 1</td>
<td>N.S.</td>
</tr>
<tr>
<td>A at b₃</td>
<td>1</td>
<td>1.83</td>
<td>N.S.</td>
</tr>
<tr>
<td>A at b₄</td>
<td>1</td>
<td>&lt; 1</td>
<td>N.S.</td>
</tr>
<tr>
<td>Error</td>
<td>83</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note 1. Renal group = A, with \(a₁ = \) HD and \(a₂ = \) CAPD; SORDS severity level = B, with \(b₁ = \) 1st quartile, \(b₂ = \) 2nd quartile, \(b₃ = \) 3rd quartile and \(b₄ = \) 4th quartile.
From Table 4.14, it can be seen that a significant difference in mean BDI-CS scores exists across the SORDS quartile groups for CAPD patients, i.e., the B at a_2 analysis (F = 3.97; d.f. = 3.76; p < .025). The mean BDI-CS scores for the SORDS quartile groups within the HD patient group did not differ significantly at the α = .05 level. Finally, mean BDI-CS scores for HD and CAPD dialysis patient groups differed significantly for only those patients at the lowest level of severity of renal disease as assessed by SORDS (i.e., the 1st quartile group only). Table 4.15 shows pairwise comparison analyses examining the specific differences in mean BDI-CS scores for the CAPD patient group.

**Table 4.15** Student-Newman-Keuls analyses of BDI-CS means for SORDS severity groups, CAPD patient group only.

<table>
<thead>
<tr>
<th>SORDS Quartile Group</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>BDI-CS Means for CAPD patients</td>
<td>4.9</td>
<td>5.8</td>
<td>8</td>
<td>16.9</td>
</tr>
</tbody>
</table>

**Note 1.** Means connected by a common underline do not differ significantly.

The results presented above in Table 4.15 show where significant differences exist between BDI-CS for SORDS severity groups within the CAPD patient group. It will be remembered that the simple main effects ANOVA reported in Table 4.14 also showed a significant difference in the mean BDI-CS scores for the lowest severity level on SORDS (i.e., 1st quartile) across the two dialysis groups. This result is simply understood by referring back to Table 4.12. The mean BDI-CS score for the 1st quartile severity group of HD patients was
3.3. The mean BDI-CS score for the 1st quartile severity group of CAPD patients was 16.9. These two means differ significantly.

The results presented above are perhaps best understood by the data presented in Figure 4.4.

**Figure 4.4** Mean BDI-CS scores for HD and CAPD patients classified by SORDS quartile standings.

![Graph showing BDI-CS scores by SORDS quartile](image)

Figure 4.4 illustrates the relationship between SORDS severity level and levels of measured depression independent of physical confounds since this series of analyses involves the BDI-CS and as such eliminates physical symptomatology.
Analyses similar to those presented in Tables 4.8 to 4.15 were also carried out using the ESRD-SI. As with SORDS, severity levels on the ESRD-SI were determined by dividing the groups into quartiles, with the lowest quartile group showing the lowest ESRD-SI scores. Table 4.16 presents the mean BDI-II scores for the quartile groupings using the ESRD-SI, divided into the HD and CAPD patient groups.

**Table 4.16** Mean BDI-II scores for HD and CAPD patients classified by ESRD-SI quartile standings.¹

<table>
<thead>
<tr>
<th>Dialysis Group</th>
<th>1ˢᵗ</th>
<th>2ʰᵈ</th>
<th>3ʳᵈ</th>
<th>4ᵗʰ</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>HD</td>
<td>8.6 (13)</td>
<td>7.6 (11)</td>
<td>17.6 (13)</td>
<td>15.3 (12)</td>
<td>12.4 (49)</td>
</tr>
<tr>
<td>CAPD</td>
<td>14.2 (9)</td>
<td>11.9 (11)</td>
<td>15.7 (11)</td>
<td>11.3 (11)</td>
<td>13.2 (42)</td>
</tr>
<tr>
<td>Total</td>
<td>10.9 (22)</td>
<td>9.7 (22)</td>
<td>16.8 (24)</td>
<td>13.4 (23)</td>
<td>12.8 (91)</td>
</tr>
</tbody>
</table>

¹. Mean BDI-II scores are followed by the number of patients in the particular cell shown in parentheses.

The 2-way ANOVA of the means shown in Table 4.16 is presented in Table 4.17.

**Table 4.17** 2-way ANOVA of BDI-II scores for HD and CAPD patients classified by ESRD-SI quartile standings.

<table>
<thead>
<tr>
<th>Source</th>
<th>d.f.</th>
<th>F-ratio</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Renal Group</td>
<td>1</td>
<td>&lt; 1</td>
<td>N.S.</td>
</tr>
<tr>
<td>Severity Level</td>
<td>3</td>
<td>1.62</td>
<td>N.S.</td>
</tr>
<tr>
<td>Group by Severity</td>
<td>3</td>
<td>&lt; 1</td>
<td>N.S.</td>
</tr>
<tr>
<td>Error</td>
<td>83</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>91</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The results in Table 4.17 show that there is no significant relationship between severity levels as assessed by the ESRD-SI and mean scores on the BDI-II for the two dialysis patient groups. A similar analysis was conducted using the BDI-CS scores, and that analysis also showed no significant differences. For economy of presentation, these results are not presented.

Finally, the relationship between depression and perception of health status (as assessed by the SF-36) was assessed for the HD patient group (only one CAPD patient was administered the SF-36, eliminating this dialysis group from these analyses). Similar to previous analyses, measured depression levels were assessed at varying levels of health status, with health status assessed by SF-36 scores. Quartile groupings using the PHC, MHC and GHC scales from the SF-36 were determined for the HD patient group. The resulting quartile groupings were then used to examine mean BDI-II and BDI-CS scores using a one-way ANOVA. The quartile levels represent from lowest to highest those patients who have the best to worst self-assessed health and general well-being (i.e., the first quartile are those who have the most positive self-ratings and the fourth quartile are those who have the most negative self-ratings).

The ANOVA results and subsequent pairwise comparison analyses are summarized in Tables 4.18 to 4.20.
Table 4.18 ANOVA and pairwise comparison results: Mean BDI-II and BDI-CS scores for PHC health status quartile levels for the HD sample.

<table>
<thead>
<tr>
<th>Variable</th>
<th>F-ratio</th>
<th>p</th>
<th>SF-36, PHC Quartile Levels</th>
</tr>
</thead>
<tbody>
<tr>
<td>BDI-II</td>
<td>11.149</td>
<td>&lt; .0005</td>
<td>1&lt;sup&gt;st&lt;/sup&gt;</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2.9</td>
</tr>
<tr>
<td>BDI-CS</td>
<td>8.659</td>
<td>&lt; .0005</td>
<td>1&lt;sup&gt;st&lt;/sup&gt;</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>0.69</td>
</tr>
</tbody>
</table>

Student-Newman-Keuls: α = .05.<sup>2</sup>

---

Note 1. All F-ratios have d.f. = 3, 44.

Note 2. Means connected by a common underline do not differ significantly.

The results presented in Table 4.18 show where significant differences exist between the BDI-II and the BDI-CS for PHC quartile levels within the HD patient group. For both versions of the depression measure, significant differences were observed at different quartile levels of the PHC. The 2<sup>nd</sup>, 3<sup>rd</sup> and 4<sup>th</sup> quartile levels did not differ significantly on either the BDI-II or the BDI-CS. Patients at the 1<sup>st</sup> or best self-perceived physical health status quartile level showed significantly lower scores on depression measures than patients at higher quartile levels suggesting that patients with better self-perceived physical health and functioning status are less depressed than patients who perceive themselves to be in poorer physical health.
Table 4.19. ANOVA and pairwise comparison results: Mean BDI-II and BDI-CS scores for MHC health status quartile levels for the HD sample.

<table>
<thead>
<tr>
<th>Variable</th>
<th>F-ratio</th>
<th>p</th>
<th>1&lt;sup&gt;st&lt;/sup&gt;</th>
<th>2&lt;sup&gt;nd&lt;/sup&gt;</th>
<th>3&lt;sup&gt;rd&lt;/sup&gt;</th>
<th>4&lt;sup&gt;th&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>BDI-II</td>
<td>14.564</td>
<td>&lt;.0005</td>
<td>3</td>
<td>9.5</td>
<td>14.8</td>
<td>24.4</td>
</tr>
<tr>
<td>BDI-CS</td>
<td>15.447</td>
<td>&lt;.0005</td>
<td>0.77</td>
<td>5.3</td>
<td>8.8</td>
<td>17.8</td>
</tr>
</tbody>
</table>

Student-Newman-Keuls: α = .05<sup>2</sup>

Note 1. All F-ratios have d.f. = 3, 45.
Note 2. Means connected by a common underline do not differ significantly.

The results presented in Table 4.19 show a similar pattern within the HD patient group for the BDI-II at different quartile levels of the MHC scale. Again, the 1<sup>st</sup> quartile level shows the lowest BDI-II scores suggesting that patients whose self-assessed well-being is high are also those patients who have low scores on the BDI-II. Similarly, BDI-CS scores at the 4<sup>th</sup> quartile of the MHC scale are significantly higher than at other mental health status quartile levels. These results suggest that patients who perceive themselves to have poor mental health status also report higher levels of depression on the BDI-CS than patients whose MHC scores reflect better self-perceived general well being.
Table 4.20  ANOVA and pairwise comparison results: Mean BDI-II and BDI-CS scores for GHC health status quartile levels for the HD sample.

<table>
<thead>
<tr>
<th>Variable</th>
<th>F-ratio</th>
<th>p</th>
<th>Student-Newman-Keuls: α = .05²</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>SF-36, GHC Quartile Levels</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1st  2nd  3rd  4th</td>
</tr>
<tr>
<td>BDI-II</td>
<td>14.564</td>
<td>&lt; .0005</td>
<td>2.18  6.8  14.64  26.91</td>
</tr>
<tr>
<td>BDI-CS</td>
<td>15.447</td>
<td>&lt; .0005</td>
<td>0.55  3    9.1    19.1</td>
</tr>
</tbody>
</table>

Note 1. All F-ratios have d.f. = 3, 44.
Note 2. Means connected by a common underline do not differ significantly.

The results presented above in Table 4.20 show where significant differences exist between the BDI-II and the BDI-CS for GHC quartile levels within the HD patient group. For both measures of depression, scores in the first and second quartile level of the GHC scale are significantly lower than scores in the 3rd and 4th quartile levels. In other words, patients who report relatively positive perceptions of their general health status also have lower scores on depression measures than patients who report a more negative assessment of general health and well-being as measured by the GHC scale. All results in comparing BDI-II and BDI-CS scores are to have been expected given the high correlations earlier reported between these measures.

To rule out the potential confounds of dialysis duration and age as being responsible for the earlier findings of interactions between SORDS severity levels and dialysis treatment groups on reported depression, another series of
ANOVAs was carried out again utilizing SORDS severity quartiles. Tables 4.21 and 4.22 show duration and age statistics respectively for HD and CAPD patients grouped by SORDS severity quartiles. Tables 4.23 and 4.24 show the ANOVA results for the data in Tables 4.21 and 4.22.

Table 4.21  Mean dialysis duration for HD and CAPD patients classified by SORDS quartile standings.¹.

<table>
<thead>
<tr>
<th>Dialysis Group</th>
<th>1ˢᵗ</th>
<th>2ⁿᵈ</th>
<th>3ʳᵈ</th>
<th>4ᵗʰ</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>HD</td>
<td>33.0 (14)</td>
<td>42.1 (14)</td>
<td>29.4 (10)</td>
<td>38.9 (11)</td>
<td>36.2 (49)</td>
</tr>
<tr>
<td>CAPD</td>
<td>20.7 (9)</td>
<td>18.6 (12)</td>
<td>31.6 (12)</td>
<td>27.7 (9)</td>
<td>24.7 (42)</td>
</tr>
<tr>
<td>Total</td>
<td>28.2 (23)</td>
<td>31.3 (26)</td>
<td>30.6 (22)</td>
<td>33.9 (20)</td>
<td>30.9 (91)</td>
</tr>
</tbody>
</table>

Note 1. Mean dialysis duration is followed by the number of patients in parentheses.

Table 4.22  Mean age for HD and CAPD patients classified by SORDS quartile standings.¹.

<table>
<thead>
<tr>
<th>Dialysis Group</th>
<th>1ˢᵗ</th>
<th>2ⁿᵈ</th>
<th>3ʳᵈ</th>
<th>4ᵗʰ</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>HD</td>
<td>59.7 (14)</td>
<td>58.1 (14)</td>
<td>57.2 (10)</td>
<td>58.6 (11)</td>
<td>58.5 (49)</td>
</tr>
<tr>
<td>CAPD</td>
<td>51.3 (9)</td>
<td>57.3 (12)</td>
<td>58.8 (12)</td>
<td>63.1 (9)</td>
<td>56.3 (42)</td>
</tr>
<tr>
<td>Total</td>
<td>56.4 (23)</td>
<td>57.8 (26)</td>
<td>55.4 (22)</td>
<td>60.6 (20)</td>
<td>57.5 (91)</td>
</tr>
</tbody>
</table>

Note 1. Mean age is followed by the number of patients in parentheses.

As seen on the following page in Tables 4.23 and Table 4.24, there were no significant differences in average duration or age across SORDS on the severity quartile groups. This may be because of the heterogeneity of the sample on the dependent variables (dialysis duration and age).
Table 4.23 2-way ANOVA of dialysis duration classified by SORDS severity quartiles.

<table>
<thead>
<tr>
<th>Source</th>
<th>d.f.</th>
<th>F-ratio</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Renal Group</td>
<td>1</td>
<td>3.35</td>
<td>N.S.</td>
</tr>
<tr>
<td>Severity Level</td>
<td>3</td>
<td>&lt;1</td>
<td>N.S.</td>
</tr>
<tr>
<td>Group by Severity</td>
<td>3</td>
<td>&lt;1</td>
<td>N.S.</td>
</tr>
<tr>
<td>Error</td>
<td>83</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>91</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 4.24 2-way ANOVA of age classified by SORDS severity quartiles.

<table>
<thead>
<tr>
<th>Source</th>
<th>d.f.</th>
<th>F-ratio</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Renal Group</td>
<td>1</td>
<td>&lt;1</td>
<td>N.S.</td>
</tr>
<tr>
<td>Severity Level</td>
<td>3</td>
<td>&lt;1</td>
<td>N.S.</td>
</tr>
<tr>
<td>Group by Severity</td>
<td>3</td>
<td>&lt;1</td>
<td>N.S.</td>
</tr>
<tr>
<td>Error</td>
<td>83</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>91</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

These results demonstrate that interactions between depression, severity of illness and dialysis group are independent of the influence of confounding variables such as age and time on dialysis and provide further evidence of SORD’s validity and utility in psychosocial research with renal patients.

4.7 Research Hypothesis 5 (Reliability Analyses)

Reliability analyses were performed for 22 CAPD patients by two independent raters (SORDS1 and SORDS2 and ESRD-SI1 and ESRD-SI2
respectively). It was expected that reliability estimates would be high. A summary of the reliability analyses may be seen in Table 4.25.

**Table 4.25** Inter-rater reliability correlations.

<table>
<thead>
<tr>
<th></th>
<th>SORDS1</th>
<th>SORDS2</th>
<th>ESRD-SI1</th>
<th>ESRD-SI2</th>
</tr>
</thead>
<tbody>
<tr>
<td>SORDS1</td>
<td>-</td>
<td>0.326</td>
<td>0.653**</td>
<td>0.512**</td>
</tr>
<tr>
<td>SORDS2</td>
<td>0.326</td>
<td>-</td>
<td>-0.084</td>
<td>0.461*</td>
</tr>
<tr>
<td>ESRD-SI1</td>
<td>0.653**</td>
<td>-0.084</td>
<td>-</td>
<td>0.498*</td>
</tr>
<tr>
<td>ESRD-SI2</td>
<td>0.512**</td>
<td>0.461*</td>
<td>0.498*</td>
<td>-</td>
</tr>
</tbody>
</table>

**Note 1.** All correlations are based on n = 22.

* Correlations significant at the .05 level.
** Correlations significant at the .01 level.

Surprisingly, correlations between two independent raters on SORDS (SORDS1 and SORDS2) were non-significant ($r = .326, p = .075$). Interestingly, correlations between SORDS1 and both ratings of the ESRD-SI were high and significant. However, ESRD-SI1 scores were uncorrelated with SORDS2 suggesting that the first rater (designated by ‘1’) rated items in a more consistent manner than the second rater. An item by item examination of the reliability data supported this view. In addition, ratings from the second rater were characterized by a higher standard deviation than those of the first rater.

Although these data appear to belie previous estimates of reliability, the correlations between SORDS and other measures in this study can be interpreted to imply reliability. For example, it will be remembered that SORDS correlated significantly with the ESRD-SI. SORDS scores were shown to differ significantly for various renal patient groups. Relationships were also observed
between SORDS scores and depression as assessed by the BDI-II. Thus, the low inter-rater reliability estimates seen in Table 4.25 suggest problems with the reliability assessment process.

One difficulty with the reliability study was that the second rater began rating the patients on the SORDS and ESRD-SI scales approximately nine months after the BDI-II data was collected. In early SORDS research, when raters were coached in using SORDS, reliability correlations were high suggesting that explicit, written directions for using SORDS are necessary. This will be discussed later in greater detail.

As a final comment regarding assessment of SORDS reliability, please note that reliability models assuming homogeneity of test content (KR-20 and Coefficient α) are not appropriate for an instrument such as SORDS or the ESRD-SI. Item content across both measures is instead heterogeneous, which is to say that a patient's standing on one item is relatively independent of that same patient's standing on other items. For example, the fact that a patient suffers from hypertension, has little bearing on whether or not a patient has coronary heart disease. Reliability estimates based on an assumption that all test items assess the same underlying content area (or factor in the sense of factor analysis) are inappropriate for measures such as SORDS and the ESRD-SI.
5. Discussion

This study examined SORDS' reliability and validity and its relevance as a research tool assessing the psychological effect of illness severity. The results were encouraging and support the use of SORDS as a research instrument which assesses disease severity in ESRD.

Usually, discussions of reliability and validity present reliability evidence first, followed by evidence for validity. That will be reversed in this discussion, primarily because evidence for the validity of SORDS is more clear than evidence for reliability. That said, it must be remembered that reliability is a necessary precondition for validity. Thus, evidence for the validity for SORDS directly implies the existence of reliability. Clearly, this study failed to show empirical evidence for the inter-rater reliability of SORDS. There are several possible reasons for this which will be discussed in greater detail later in this section. Lack of reliability evidence notwithstanding, SORDS has correlated strongly in the expected direction with other well-researched measures. Therefore, it is argued that since SORDS has exhibited stability in other analyses, unfavorable results from the reliability study are not justification for concluding that SORDS is unreliable.

The validity of SORDS was supported by several results. These were: (1) the significant correlation between SORDS and the ESRD-SI in various renal
patient groups; (2) the demonstration of expected differences in average SORDS scores for patients in different treatment groups (i.e., pre-dialysis versus patients requiring dialysis); (3) the demonstration of expected relationships between SORDS scores and patient's self-perceptions of decreased physical health and functioning as measured by the SF-36; and (4) the demonstration of the potential utility of SORDS in psychosocial research with renal patients. Each of these results will be discussed in turn.

The moderately high correlation between SORDS and the ESRD-SI provides supportive evidence for convergent validity. One possible attenuating factor in these correlations is the presence of a renal dysfunction dimension on SORDS but not the ESRD-SI. However, even when the renal dysfunction dimension was eliminated from SORDS (creating SORDS-K scores) the relationship between the ESRD-SI and scores across the remaining SORDS items remained essentially the same.

A second possible attenuating factor is the inherent differences in construction and content coverage of the two instruments. A comparison of items covered by both SORDS and the ESRD-SI reveals that SORDS covers each individual disease category more comprehensively than does the ESRD-SI. This difference may explain differences in sensitivity as discussed in the following section.

SORDS was sensitive to differences among patients assigned to different treatment groups. As such, SORDS is potentially sensitive to different diagnoses (e.g., CRF and not requiring dialysis treatment versus ESRD and
requiring dialysis). It was expected that since high scores on SORDS and the ESRD-SI are associated with increasing severity of illness, scores on both instruments should be significantly lower for patients with renal dysfunction not yet requiring dialysis (the Pre-D group) than for those patients in later stages of ESRD, and receiving dialysis. While this was confirmed for SORDS, the ESRD-SI did not detect differences between dialysis and pre-dialysis groups.

SORDS scores support the commonly held definition of ESRD versus CRF, namely that ESRD patients suffer from more serious renal failure and are referred for dialysis literally to keep them alive while CRF patients show signs of renal dysfunction but are able to produce and excrete urine without dialysis. SORDS scores show distinct, statistically significant differences between treatment and non-treatment groups, thus demonstrating the capacity of SORDS to measure early symptoms of renal failure. In contrast, the ESRD-SI measures illness severity in dialysis patients only as evidenced by the absence of renal function items and the inclusion of ‘access & dialysis events (hence the name “End-Stage Renal Disease - Severity Index”). As a result, the ESRD-SI suffers from too low a ceiling and too high a floor and did not detect differences among the three study samples.

An additional point in favor of SORDS is that scaling procedures used in its early development were such that scores on individual items more accurately reflect the medical community’s view of the impact of individual disease on a person’s life.
A possible criticism of a comparison of SORDS scores for the Pre-D, HD and CAPD samples is that the differences among groups may be solely attributable to differences in kidney function. In other words, the presence of scores reflecting kidney dysfunction (e.g., creatinine clearance, gfr, and urine volume) could inflate scores on the severity measures for the dialysis groups. A one-way ANOVA showed that mean SORDS-K scores for the three samples were found to be marginally significantly different. Therefore, it cannot be said that SORDS greater sensitivity as compared to the ESRD-SI to differences among treatment groups is due entirely to the presence of kidney function items in SORDS.

SORDS and ESRD-SI scores were related to increasing disease severity and patients’ self-perceptions of decreased physical health and functioning as measured by the SF-36. SORDS and scores on the PHC and GHC for the HD sample were weakly correlated, and as expected there were no significant correlations found between SORDS scores and scores on the MHC. When items measuring kidney dysfunction were eliminated, the results were similar except for the presence of a significant correlation between scores on SORDS-K and scores on the PHC for combined groups. Interestingly, correlations between SORDS and the PHC and GHC scale scores were lower than correlations between these scales and the ESRD-SI. However, scores between the ESRD-SI and the MHC scale were not correlated.

These results indicate that higher scores on SORDS as well as the ESRD-SI were marginally related to lower self-perception of physical
functioning as assessed by the SF-36 composite scores. Correlations between the SF-36 and measures of renal disease severity provide support for the divergent validity of both SORDS and the ESRD-SI. Specifically, measures such as the SF-36, while reflecting variation in self-perceived health status, also reflect the individual’s level of adjustment to their condition as evidenced by high correlations between the SF-36 and the BDI-II. Thus, lower correlations between the SF-36 scales and measures of renal disease severity are to be expected as SORDS and the ESRD-SI are objective measures of physical health status that are independent of psychosocial influences.

The utility of SORDS in psychosocial research with renal patients was exemplified by a finding that severity of renal disease has differential impact on measured levels of depression for HD versus CAPD patients. Specifically, at the lowest level of illness severity as assessed by SORDS, CAPD patients were significantly more depressed than patients receiving in-hospital HD at the same severity level. The average BDI-II score obtained by the CAPD group placed these patients within the moderate range of depression as assessed by the BDI-II. This finding was independent of the potentially confounding influences of dialysis duration or age, and suggests SORDS has the ability to identify a potential relationship between adjustment to treatment and illness severity.

These results notwithstanding, it must be acknowledged that the research reported in this dissertation has focused on the utility of SORDS as a measure which would complement psychosocial research with renal patients. Thus, the findings discussed above should be viewed as showing an example
of how SORDS can be used in such research. Specifically, the issue of depression in renal patients needs further exploration before any definitive conclusions can be drawn with respect to illness severity and levels of depression.

Future studies examining time on dialysis are necessary before more definitive conclusions can be drawn. Because such variables as time on dialysis were not standardized for this sample, the finding that increased depression is observed at the lowest level of disease severity needs further investigation.

Because SF-36 scores were not administered to the CAPD group in this study, it is difficult to know why these patients showed higher depression scores at the lowest level of illness severity. However, the SF-36 and the BDI-II are highly correlated and so one might expect that had SF-36 scores been available, we may well have observed that those patients who were least severely ill on SORDS might have also rated themselves as having poorer health status on the SF-36 than those with higher SORDS scores. In other words, the SF-36 may have mirrored the BDI-II results from the HD group.

If indeed these patients are those more recently referred for dialysis, the referral then also represents a recent increase in disease severity. As such, patients may be for the first time contemplating the terminal nature of progressive renal failure, and thus experiencing increased illness intrusiveness. It is also possible that these patients may have difficulty reconciling their lack of other problems separate from kidney dysfunction with the constant presence of the treatment apparatus and its effects. As such, these patients may be still in
the process of adjusting to the progressive nature of their illness. This can only be confirmed in subsequent studies with CAPD patients with SF-36 scores and standardized time on dialysis.

These results point out the importance of having a measure of self-reported health status to achieve a full understanding of a person's condition. A full understanding requires knowledge of how a person views their condition but it is also important to know their physiological status independent of self-perception. The use of physiological measures of disease severity that are independent of psychosocial influences such as SORDS thus complement measures of general health status such as the SF-36.

There are several psychosocial implications of this research. BDI-II scores for HD patients at various levels of severity are not significantly different, however the results of this research suggest that this group of patients may be at risk of developing depression as disease severity increases. Conversely, for CAPD patients, levels of depression at higher levels of severity are significantly lower than at the lowest disease severity level demonstrating a tendency to become less depressed as the disease progresses.

According to local dialysis assignment practices, patients at the lowest level of severity are likely to be those newly referred for dialysis, and in particular, CAPD (G.B. Pylypchuk, personal communication, February 19, 2001). As such, they may be coming to terms with the implications of living with a progressive, chronic illness and the consequences of a lifelong treatment. This implies that psychological adaptation to the diagnosis and the disease
process may be taking place in several stages that are related to different levels of disease severity.

Patients are routinely assigned to either HD or CAPD based on clinical judgment of increasing severity of illness, under the assumption that patients will function best in their own environments. It is assumed that for these patients illness severity is not of a physically disabling degree and does not require more intensive medical monitoring (G.B. Pylypchuk, personal communication, February 12, 2001). This then leads to the assumption that such patients are better able to manage their own renal disease treatment. However, it is these patients who obtained BDI-II scores in the moderate range of depression.

Despite the prevailing belief that the least severely ill patients are prescribed CAPD and those more severely ill receive in-hospital HD dialysis, our results demonstrated little difference in illness severity between the two treatment groups in this study. The economically based trend towards community based medical practices may be supporting practices such that increasingly ill patients are being treated by the more cost-effective CAPD without the provision sufficient psychosocial assessment and support in the early stages of illness severity. The strong cultural ideology of individual responsibility and autonomy in western societies also places a high value on caring for oneself, and as such a poor match between the patient and prescribed dialysis treatment may result in poor adjustment and increased burden on both patients and their families. As such, competition for health care
funding may have implications for patients' psychosocial adaptation to life-long treatment.

The study results also contradict the popular notion put forth by Eitel (1995) and others (Sacks et al., 1990; Griffin et al., 1995) that as disease severity increases (as measured by the ESRD-SI), the burden of illness and levels of depression increase with increased behavioral control over treatment. In Sacks' (1990) study, the patient's depression level was determined by the cognitive items of the BDI (Beck, 1967), and disease severity was assessed by Plough's (1985) ESRD Severity Coefficient, while Eitel and colleagues (1995) used the ESRD-SI. It was found that the level of depression was more strongly related to the patient's perception of illness intrusiveness as assessed by the Illness Effects Questionnaire (IEQ) (Peterson, 1989) than the objective physical illness variables, a result that may have been influenced by the presence of psychosocial confounds in Plough's (1985) measure and the sensitivity of the ESRD-SI.

It should also be remembered that Plough's measure does not reflect the patient's current severity of illness, and according to the results of the present study, the ESRD-SI may not be sufficiently sensitive to detect non-linear relationships. The present study has demonstrated that the use of instruments less sensitive than SORDS to differences among treatment or pre-treatment groups may obscure interactional nature of the relationship between psychological variables, treatment type and disease severity.
The reliability of SORDS was not confirmed by this study. However, while the correlation between SORDS scores obtained by two separate raters was low and non-significant, the very nature of the items on SORDS (objective, physiologically based indicators of various disorders) leads to a conclusion that different SORDS scores obtained from a different rater for the same patient are likely the result of raters inadvertently using different sources of information. In the current study, this does seem to have occurred and may be the result of differing rating procedures between the two examiners.

Due to conflicting schedules, the second rater was not recruited until near the completion of the study. Since her ratings were by necessity derived from chart data, this required the second examiner to search for information in medical charts that was gathered six months previously. In this case, feedback from the second rater suggests that the accuracy of the ratings was dependent on the condition of the patient file. Some files contained less information on concomitant diseases and the information was less legible than that in other files. The first rater rated patients also from chart data but did so within a short time after they had been assessed in his clinic. As such, this rater used patient files only to supplement first hand knowledge of the patients medical condition. In view of these results, it must be concluded that the use of SORDS with medical chart data at this time is problematic, and should be used only by medical practitioners who are aware of patients' standing on SORDS variables.

It remains necessary to empirically demonstrate the reliability of SORDS. In addition, the following changes should be considered to improve upon the
existing reliability of the measure: (1) development of a manual with clear rating instructions for each item would also increase reliability and reduce procedural differences in data collection; (2) providing raters a brief training seminar to address specific questions and increase clarity of rating instructions; and (3) inclusion of a case example. Additionally, a study could be carried out to determine the most reliable and efficient means of collecting data. For example, a study might collect data using SORDS from medical files and compare results to data collected directly from patients.

As a final comment regarding the reliability of SORDS, it needs to be pointed out again that correlations between SORDS and other measures such as the BDI-II and ESRD-SI would not have been possible were SORDS lacking reliability. Additionally, the validity results discussed above strongly infer that SORDS is a reliable instrument. Nevertheless, it is clear that continuing research is need to definitively establish SORDS reliability.

Future SORDS research should include: (1) collection of additional demographic details; (2) longitudinal studies to explore the relationship of SORDS scores and death; (3) collection of pre- and post-transplant SORDS scores; (4) a focus on pre-dialysis patients to assess the utility of SORDS as a primary diagnostic tool in making primary treatment decisions; (5) collection of additional psychosocial data such as locus of control as applied to health behavior, perceived social support, behavioral as well as physiological compliance; and (6) exploration of the impact of various psychosocial
interventions such as compliance education. Each recommendation is discussed next in turn.

Keegan et al. (1983) found that demographic data such as the need to change one’s place of residence in order to obtain dialysis, unmarried status, and an unskilled occupation with consequent post-treatment unemployment were important social stressors. In addition, primary diagnosis, race, and time since initial referral to a nephrology clinic could be collected. There may be a higher rate of diabetes in the Aboriginal population, therefore there are potentially more ESRD patients of this type in this province. This was not anticipated at the outset of the study, so this data was not collected. However, this should be done in the future.

It would also be desirable to conduct longitudinal studies to explore the relationship of SORDS scores and death. A preliminary analysis of SORDS conducted in the mid-1980's using randomly selected patients admitted to hospital (not renal patients) showed SORDS to be a powerful predictor of mortality (Baltzan et al., unpublished manuscript). Longitudinal studies would also provide valuable information regarding SORDS potential sensitivity to the dynamic nature of renal disease. For example, as a person’s renal function deteriorates, SORDS scores should increase; conversely, SORDS scores should decrease subsequent to renal transplant, thus reflecting successful treatment outcome.

A significant limitation of this study was the relatively small number of pre-dialysis patients. Future research with SORDS should include a focus on
this particular group of patients, and assess the utility of SORDS as a primary diagnostic tool in making primary treatment decisions. Such research, if successful, would provide strong evidence for SORDS validity. For this to be done successfully, it is likely that multi-center trials would be required.

Collection of additional psychosocial data such as locus of control as applied to health behavior, perceived social support, and compliance could be useful for assessment and treatment of renal patients and their families prior to assignment to CAPD or HD. Future studies should examine the main and interactive effects of health locus of control, social support, and illness severity with regard to depression and compliance while standardizing patients on time on dialysis. For example, at present the influence of various psychosocial variables on the interaction between depression, dialysis type and disease severity remains purely speculative. The effect of dialysis duration on psychosocial adjustment to illness effects and treatment is also uncertain as a result of the heterogeneity of the sample with respect to this variable.

Should future research reveal that SORDS is sensitive to changes in renal disease status, it could be used in research examining the impact of various psychosocial treatments on patients’ and their families adjustment to progressive disease and life on dialysis treatment.

Modifications to SORDS may increase the likelihood of improved reliability in future psychometric studies. In consultation with medical specialists involved in the original development of SORDS as well as in the present study, several suggestions for changes to SORDS were made. They include: (1)
specification of time frames for all but those items (i.e., anemia, hypertension, and hyperparathyroidism) subject to daily or frequent fluctuation; (2) elimination of glomerular filtration rate, and urine volume; and (3) inclusion of two items strongly correlated with mortality in the renal literature, specifically kinetic transfer / volume urea (a measure of dialysis adequacy) and serum albumin levels. The recommendations are discussed next.

Specification of time frames for all items (except anemia, hypertension, and hyperparathyroidism) would decrease spurious searching of medical files for item information, and thus indirectly improve reliability.

Elimination of glomerular filtration rate, and urine volume was recommended to reflect current diagnostic practices. Glomerular filtration rate values duplicate creatinine clearance values, and urine volume is no longer collected on a routine basis.

Kinetic transfer / volume urea, a measure of dialysis adequacy and serum albumin levels, two items strongly correlated with mortality in the renal literature would be added to SORDS. These values are objective and are routinely collected at each dialysis session or clinic visit (G. Pylypchuk, personal communication, December 15, 2000).

If these suggested modifications to SORDS are carried out, it would then be necessary to evaluate the resulting changes in definitions of severity levels with a view to assessing the need for re-scaling the severity levels. In other words, the current severity scale values for any revised SORDS items may no longer apply if the definitions of severity levels are modified. This would require
a replication of the original scaling procedure using panels of expert medical personnel.

In addition, the following modifications should also be made to SORDS: (1) inclusion of an open-ended, non-disease specific “other” item; and (2) inclusion of more specific rating instructions both on the SORDS form and in manual form. Addition of an open-ended, non-disease specific “other” item would allow collection of information relevant to the patient’s physiological health status thus capturing possible health status changes due to conditions not currently included on SORDS. The item would use a scale from “0” to “100” where 100 is defined as death and intermediate points (such as 20, 40, 60 and 80) are defined as increasing functional limitations in the areas of normal daily activities, physical limitations and mobility limitations (the same descriptors used in the original scaling of the SORDS items).

In conclusion, the results of this study demonstrated that SORDS has both divergent and convergent validity. It is sensitive to differences among treatment groups and was able to discern important interactional relationships between treatment type, disease severity and depression in renal patients. While reliability estimates were low, the stable nature of SORDS as demonstrated across various analyses suggests that it is a useful instrument in research examining psychosocial variables in the renal population.
6. References


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### APPENDIX A

#### SEVERITY OF RENAL DISEASE SCALE (SORDS)

<table>
<thead>
<tr>
<th>Anemia</th>
<th>Men</th>
<th>Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ absent ..... 133 gm/ml or more ..... 117 gm/ml or more</td>
<td>□ mild ..... 90 to 132 gm/ml or more 90 to 116 gm/ml or more</td>
<td>□ moderate ..... 60 to 89 gm/ml or more 60 to 89 gm/ml or more</td>
</tr>
<tr>
<td>□ mild ..... 90 to 132 gm/ml or more 90 to 116 gm/ml or more</td>
<td>□ moderate ..... 60 to 89 gm/ml or more 60 to 89 gm/ml or more</td>
<td>□ severe ..... 59 gm/ml or less ..... 59 gm/ml or less</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Pneumonia</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>□ mild ..... patchy airspace consolidation</td>
<td>□ moderate ..... segmental/lobar consolidation</td>
<td>□ severe ..... multiple lobe involvement</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Pleuritis</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>□ mild ..... pleurisy without effusion</td>
<td>□ moderate ..... pleurisy with small effusion(s)</td>
<td>□ severe ..... pleurisy with large effusion(s)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Pulmonary embolism</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>□ minor ..... X-ray evidence only</td>
<td>□ major ..... X-ray evidence plus clinical symptoms</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Pulmonary edema</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>□ mild ..... upper lobe vessel changes</td>
<td>□ moderate ..... interstitial edema</td>
<td>□ severe ..... airspace edema</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Coronary heart disease</th>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td>(based on evidence from any of the following:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(a) EKG - recent or old myocardial damage: (b) positive thallium scan;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>and/or (c) positive coronary angiogram</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ minimal CHD</td>
<td>□ moderate to severe CHD</td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Angina pectoris</th>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td>□ moderate ..... angina present, but only with exertion</td>
<td>□ severe ..... angina present at rest</td>
<td></td>
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<table>
<thead>
<tr>
<th>Hypertension</th>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Age: 45 to 40</td>
<td>41 to 60</td>
<td>61 or older</td>
</tr>
<tr>
<td>□ mild ..... 140/90 to 159/104 160/95 to 169/104 165/100 to 174/109</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ moderate ..... 160/95 to 199/129 170/105 to 199/129 175/110 to 199/129</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ severe ..... 200/130 or higher 200/130 or higher 200/130 or higher</td>
<td></td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Peripheral ischemia</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>□ moderate ..... present, but only with exertion</td>
<td>□ severe ..... present at rest</td>
<td></td>
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<table>
<thead>
<tr>
<th>Pericarditis</th>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td>□ present</td>
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<table>
<thead>
<tr>
<th>Pruritis</th>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td>□ mild ..... symptoms of itch</td>
<td>□ moderate ..... evidence of scratching or rubbing</td>
<td>□ severe ..... evidence of excoriation</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Diabetes</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>□ present but not requiring insulin</td>
<td>□ present and only controllable through insulin injections</td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Hyperparathyroidism</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>□ present, calcium levels of 11 to 13 mg/100 ml; or moderate elevation of serum PTH (2 to 3 times normal levels)</td>
<td>□ present, calcium levels of more than 13 mg/100 ml; or severe elevation of serum PTH (4 times normal levels or more)</td>
<td></td>
</tr>
</tbody>
</table>
Non-specific nausea and vomiting
- mild . . . . nausea at least once a day
- moderate . vomiting or vomiting and nausea at least once a day

Ascites
- present

Esophagitis
- present

Hepatitis
- present . . any evidence of same

Peptic ulcer
- mild . . . . X-ray evidence only, no symptoms
- moderate . X-ray evidence + clinical symptoms; slow blood loss
- severe . . . X-ray evidence + clinical symptoms; hemorrhage + perforations

Rapid weight loss (over past six weeks; all dry weights)
- mild . . . . 5% to 10% of body weight lost
- moderate . 11% to 20% of body weight lost
- severe . . . more than 20% of body weight lost

Osteo dystrophy
- moderate . present, but no fractures
- severe . . . present with fractures

Aseptic necrosis
- mild . . . . no symptoms; early X-ray evidence
- moderate . mild intermittent groin pains; X-ray evidence clear
- severe . . . continuous pain; crutches necessary; arthritis on X-ray

Osteoporosis
- moderate . present, but no fractures
- severe . . . present with fractures

Cerebrovascular accident severity (based on Glasgow Coma Scale)
- mild . . . . 1 to 6 points
- moderate . . 7 to 12 points
- severe . . . 13 points or more

Peripheral nerve disease: Scaling instructions - E.M.G. velocities slowest of either the peroneal or posterior tibial nerves.
- mild . . . . E.M.G. velocity of 35 m/sec to 39 m/sec
- moderate . . E.M.G. velocity of 30 m/sec to 34 m/sec
- severe . . . E.M.G. velocity of 29 m/sec or less

Creatinine clearance problems
- mild . . . . 21 to 69 ml per minute
- moderate . . 5 to 20 ml per minute
- severe . . . 0 to less than 5 ml per sec - requires dialysis

Glomerular filtration rate problems
- mild . . . . 21 to 69 ml per minute
- moderate . . 5 to 20 ml per minute
- severe . . . 0 to less than 5 ml per sec - requires dialysis

Urine volume problems
- mild . . . . 500 ml per day to 999 ml per day
- moderate . . 100 ml per day to 499 ml day
- severe . . . 0 ml per day to 99 ml per day
## Appendix B

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

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

<table>
<thead>
<tr>
<th>Disease</th>
<th>Absent</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart Disease</td>
<td></td>
<td>e.g.: occasional angina of effort</td>
<td>e.g.: angina with or without CHF</td>
<td>e.g.: angina or incapacitating severe CHF on minimal exercise</td>
</tr>
<tr>
<td>Cerebral Vascular Disease</td>
<td></td>
<td>e.g.: occasional evidence of TIA or amaurosis fugax</td>
<td>e.g.: recurrent TIA</td>
<td>e.g.: stroke with deficit</td>
</tr>
<tr>
<td>Peripheral Vascular Disease</td>
<td></td>
<td>e.g.: occasional pain on exercise</td>
<td>e.g.: pain with mild activity - i.e.: walking half a block</td>
<td>e.g.: leg pain at night, at rest, or extensive ulceration</td>
</tr>
<tr>
<td>Peripheral Neuropathy</td>
<td></td>
<td>e.g.: paresthesiae</td>
<td>e.g.: sensory changes</td>
<td>e.g.: myopathy</td>
</tr>
<tr>
<td>Bone Disease</td>
<td></td>
<td>e.g.: minimal symptoms, biochemical + radiological changes</td>
<td>e.g.: bone pain consistently present; radiological changes obvious</td>
<td>e.g.: pathological fractures</td>
</tr>
<tr>
<td>Respiratory Disease</td>
<td></td>
<td>e.g.: SOB with exertion periodic bronchitis</td>
<td>E.G.: SOB with mild exercise, frequent respiratory infections</td>
<td>e.g.: SOB at rest</td>
</tr>
<tr>
<td>Visual Impairment (rate vision)</td>
<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>
<td>e.g.: unable to read even large print, unable to move without aid, cannot watch television</td>
</tr>
<tr>
<td>Autonomic Neuropathy &amp; G.I. Disease</td>
<td></td>
<td>e.g.: nausea, feelings of weakness post-dialysis</td>
<td>e.g.: nausea, vomiting, occasional syncope</td>
<td>e.g.: vomiting every dialysis, syncope diatrisis</td>
</tr>
<tr>
<td>Access &amp; Dialysis Events</td>
<td></td>
<td>e.g.: occasional malplacement, easily correctable</td>
<td>e.g.: peritonitis, catheter infection, poor flow</td>
<td>e.g.: membrane failure, multiple bouts peritonitis, thrombosis, pulmonary haemorrhage</td>
</tr>
<tr>
<td>Diabetes (rate severity)</td>
<td></td>
<td>e.g.: insulin not required</td>
<td>e.g.: occasional hypoglycaemia, high blood sugar</td>
<td>e.g.: frequent hypoglycaemia or ketoacidosis</td>
</tr>
<tr>
<td>Other (specify)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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Appendix C
BDI-II
Instructions: This questionnaire consists of 21 groups of statements. Please read each group of statements carefully, and then pick out the one statement in each group that best describes the way you have been feeling during the past two weeks, including today. Circle the number beside the statement you have picked. If several statements in the group seem to apply equally well, circle the highest number for that group. Be sure that you do not choose more than one statement for any group, including Item 16 (Changes in Sleeping Pattern) or Item 18 (Changes in Appetite).

<table>
<thead>
<tr>
<th>1. Sadness</th>
<th>6. Punishment Feelings</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 I do not feel sad.</td>
<td>0 I don’t feel I am being punished.</td>
</tr>
<tr>
<td>1 I feel sad much of the time.</td>
<td>1 I feel I may be punished.</td>
</tr>
<tr>
<td>2 I am sad all the time.</td>
<td>2 I expect to be punished.</td>
</tr>
<tr>
<td>3 I am so sad or unhappy that I can’t stand it.</td>
<td>3 I feel I am being punished.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. Pessimism</th>
<th>7. Self-Dislike</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 I am not discouraged about my future.</td>
<td>0 I feel the same about myself as ever.</td>
</tr>
<tr>
<td>1 I feel more discouraged about my future than I used to be.</td>
<td>1 I have lost confidence in myself.</td>
</tr>
<tr>
<td>2 I do not expect things to work out for me.</td>
<td>2 I am disappointed in myself.</td>
</tr>
<tr>
<td>3 I feel my future is hopeless and will only get worse.</td>
<td>3 I dislike myself.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3. Past Failure</th>
<th>8. Self-Criticaleness</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 I do not feel like a failure.</td>
<td>0 I don’t criticize or blame myself more than usual.</td>
</tr>
<tr>
<td>1 I have failed more than I should have.</td>
<td>1 I am more critical of myself than I used to be.</td>
</tr>
<tr>
<td>2 As I look back, I see a lot of failures.</td>
<td>2 I criticize myself for all of my faults.</td>
</tr>
<tr>
<td>3 I feel I am a total failure as a person.</td>
<td>3 I blame myself for everything bad that happens.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4. Loss of Pleasure</th>
<th>9. Suicidal Thoughts or Wishes</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 I get as much pleasure as I ever did from the things I enjoy.</td>
<td>0 I don’t have any thoughts of killing myself.</td>
</tr>
<tr>
<td>1 I don’t enjoy things as much as I used to.</td>
<td>1 I have thoughts of killing myself, but I would not carry them out.</td>
</tr>
<tr>
<td>2 I get very little pleasure from the things I used to enjoy.</td>
<td>2 I would like to kill myself.</td>
</tr>
<tr>
<td>3 I can’t get any pleasure from the things I used to enjoy.</td>
<td>3 I would kill myself if I had the chance.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5. Guilty Feelings</th>
<th>10. Crying</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 I don’t feel particularly guilty.</td>
<td>0 I don’t cry anymore than I used to.</td>
</tr>
<tr>
<td>1 I feel guilty over many things I have done or should have done.</td>
<td>1 I cry more than I used to.</td>
</tr>
<tr>
<td>2 I feel quite guilty most of the time.</td>
<td>2 I cry over every little thing.</td>
</tr>
<tr>
<td>3 I feel guilty all of the time.</td>
<td>3 I feel like crying, but I can’t.</td>
</tr>
</tbody>
</table>
11. Agitation
0 I am no more restless or wound up than usual.
1 I feel more restless or wound up than usual.
2 I am so restless or agitated that it's hard to stay still.
3 I am so restless or agitated that I have to keep moving or doing something.

12. Loss of Interest
0 I have not lost interest in other people or activities.
1 I am less interested in other people or things than before.
2 I have lost most of my interest in other people or things.
3 It's hard to get interested in anything.

13. Indecisiveness
0 I make decisions about as well as ever.
1 I find it more difficult to make decisions than usual.
2 I have much greater difficulty in making decisions than I used to.
3 I have trouble making any decisions.

14. Worthlessness
0 I do not feel I am worthless.
1 I don't consider myself as worthwhile and useful as I used to.
2 I feel more worthless as compared to other people.
3 I feel utterly worthless.

15. Loss of Energy
0 I have as much energy as ever.
1 I have less energy than I used to have.
2 I don't have enough energy to do very much.
3 I don't have enough energy to do anything.

16. Changes in Sleeping Pattern
0 I have not experienced any change in my sleeping pattern.
1a I sleep somewhat more than usual.
1b I sleep somewhat less than usual.
2a I sleep a lot more than usual.
2b I sleep a lot less than usual.
3a I sleep most of the day.
3b I wake up 1-2 hours early and can't get back to sleep.

17. Irritability
0 I am no more irritable than usual.
1 I am more irritable than usual.
2 I am much more irritable than usual.
3 I am irritable all the time.

18. Changes in Appetite
0 I have not experienced any change in my appetite.
1a My appetite is somewhat less than usual.
1b My appetite is somewhat greater than usual.
2a My appetite is much less than before.
2b My appetite is much greater than usual.
3a I have no appetite at all.
3b I crave food all the time.

19. Concentration Difficulty
0 I can concentrate as well as ever.
1 I can't concentrate as well as usual.
2 It's hard to keep my mind on anything for very long.
3 I find I can't concentrate on anything.

20. Tiredness or Fatigue
0 I am no more tired or fatigued than usual.
1 I get more tired or fatigued more easily than usual.
2 I am too tired or fatigued to do a lot of the things I used to do.
3 I am too tired or fatigued to do most of the things I used to do.

21. Loss of Interest in Sex
0 I have not noticed any recent change in my interest in sex.
1 I am less interested in sex than I used to be.
2 I am much less interested in sex now.
3 I have lost interest in sex completely.
Appendix D
SF-36
SF-36 (Short-form Health Survey)

Part I: General health

1. In general, would you say your health is:
   (a) Excellent    (b) Very Good    (c) Good    (d) Fair    (e) Poor

2. *Compared to one year ago*, how would you rate your health in general *now*?
   (a) Much better than one year ago.
   (b) Somewhat better than one year ago.
   (c) About the same as one year ago.
   (d) Somewhat worse than one year ago.
   (e) Much worse than one year ago.

Part II: The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

3. *Vigorous activities*, such as running, lifting heavy objects, participating in vigorous sports.
   (a) Yes, Limited a lot.    (b) Yes, Limited a little.    (c) No, Not Limited at all

4. *Moderate activities*, such as moving a table, pushing a vacuum cleaner, bowling, or golf.
   (a) Yes, Limited a lot.    (b) Yes, Limited a little.    (c) No, Not Limited at all

5. Lifting, or carrying groceries.
   (a) Yes, Limited a lot.    (b) Yes, Limited a little.    (c) No, Not Limited at all

6. Climbing *several* flights of stairs.
   (a) Yes, Limited a lot.    (b) Yes, Limited a little.    (c) No, Not Limited at all

7. Climbing *one* flight of stairs.
   (a) Yes, Limited a lot.    (b) Yes, Limited a little.    (c) No, Not Limited at all

8. Bending, kneeling, or stooping.
   (a) Yes, Limited a lot.    (b) Yes, Limited a little.    (c) No, Not Limited at all

9. Walking *more than a mile*.
   (a) Yes, Limited a lot.    (b) Yes, Limited a little.    (c) No, Not Limited at all

10. Walking *several blocks*.
    (a) Yes, Limited a lot.    (b) Yes, Limited a little.    (c) No, Not Limited at all

11. Walking *one block*.
    (a) Yes, Limited a lot.    (b) Yes, Limited a little.    (c) No, Not Limited at all
12. Bathing or dressing yourself.
   (a) Yes, Limited a lot.  (b) Yes, Limited a little.  (c) No, Not Limited at all

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?

13. Cut down the amount of time you spend on work or other activities
   (a) Yes  (b) No

14. Accomplished less than you would like.
   (a) Yes  (b) No

15. Were limited in the kind of work or other activities.
   (a) Yes  (b) No

16. Had difficulty performing the work or other activities (for example, it took extra effort)
   (a) Yes  (b) No

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)?

17. Cut down the amount of time you spent on work or other activities
   (a) Yes  (b) No

18. Accomplished less than you would like
   (a) Yes  (b) No

19. Didn’t do work or other activities as carefully as usual
   (a) Yes  (b) No

20. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?
   (a) Not at all  (b) Slightly  (c) Moderately  (d) Quite a bit  (e) Extremely

21. How much bodily pain have you had during the past 4 weeks?
   (a) None  (b) Very mild  (c) Mild  (d) Moderate  (e) Severe  (f) Very Severe
22. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?
   (a) Not at all  (b) A little bit  (c) Moderately  (d) Quite a bit  (e) Extremely

These next 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:

23. Did you feel full of pep?
   (a) All of the time  (b) Most of the time  (c) A good bit of the time
   (d) Some of the time  (e) A little bit of the time  (f) None of the time

24. Have you been a very nervous person?
   (a) All of the time  (b) Most of the time  (c) A good bit of the time
   (d) Some of the time  (e) A little bit of the time  (f) None of the time

25. Have you felt so down in the dumps that nothing could cheer you up?
   (a) All of the time  (b) Most of the time  (c) A good bit of the time
   (d) Some of the time  (e) A little bit of the time  (f) None of the time

26. Have you felt calm and peaceful?
   (a) All of the time  (b) Most of the time  (c) A good bit of the time
   (d) Some of the time  (e) A little bit of the time  (f) None of the time

27. Did you have a lot of energy?
   (a) All of the time  (b) Most of the time  (c) A good bit of the time
   (d) Some of the time  (e) A little bit of the time  (f) None of the time

28. Have you felt downhearted and blue?
   (a) All of the time  (b) Most of the time  (c) A good bit of the time
   (d) Some of the time  (e) A little bit of the time  (f) None of the time

29. Did you feel worn out?
   (a) All of the time  (b) Most of the time  (c) A good bit of the time
   (d) Some of the time  (e) A little bit of the time  (f) None of the time

30. Have you been a happy person?
   (a) All of the time  (b) Most of the time  (c) A good bit of the time
   (d) Some of the time  (e) A little bit of the time  (f) None of the time
31. Did you feel tired?
   (a) All of the time    (b) Most of the time    (c) A good bit of the time
   (d) Some of the time   (e) A little bit of the time  (f) None of the time

32. 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.)?
   (a) All of the time    (b) Most of the time    (c) Some of the time
   (d) A little of the time    (e) None of the time

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

33. I seem to get sick a little easier than other people
   (a) Definitely true    (b) Mostly true    (c) Don't know    (d) Mostly false
   (e) Definitely false

34. I am as healthy as anybody I know.
   (a) Definitely true    (b) Mostly true    (c) Don't know    (d) Mostly false
   (e) Definitely false

35. I expect my health to get worse.
   (a) Definitely true    (b) Mostly true    (c) Don't know    (d) Mostly false
   (e) Definitely false

36. My health is excellent.
   (a) Definitely true    (b) Mostly true    (c) Don't know    (d) Mostly false
   (e) Definitely false
APPENDIX E
Consent Form for Participant Groups # 1 and # 2
(renal patients obtaining haemodialysis at St Paul’s Hospital and patients in the continuous ambulatory peritoneal dialysis sample)
Consent Form for Renal Patients Receiving Dialysis at St Paul’s Hospital

An Investigation of the Validity and Reliability of the Severity of Renal Disease Scale (SORDS).

Researchers:
(1) David A. Scott, PhD
   Dissertation Supervisor
   Department of Psychology
   966-6673
(2) Diana L.E. Alexander, Msc
   Doctoral Student
   Department of Psychology
   966-6673 or 975-5425
(3) George Pylypchuk, MD
   Renal Unit
   St. Paul’s Hospital

Purpose and Objectives of the Study:
The study you are being asked to participate in involves the further development of a measure of how severely ill a person is. The measure, called SORDS (Severity of Renal Disease Scale) takes into account the presence or absence of a number of health problems sometimes involved with renal disease (disease of the kidneys). Information about these problems is taken from the medical file of each patient by their physician. It is expected that those patients experiencing more severe health problems will show higher scores on the SORDS scale.

Also as part of this study, we want to compare scores on SORDS with another measure of illness severity, the ESRD-SI (End-Stage Renal Disease - Severity Index). Scores on both SORDS and the ESRD-SI are based on available medical information from each patient’s file, and as they are completed by your physician, they do not require patient interviews. Lastly, we want to compare scores from both illness severity measures with scores from other surveys of physical and emotional health. If you choose to participate, you will be asked some questions about how you feel about your present health status, and other questions about your present mood.

Consent:
The study you are participating in involves patients who are currently receiving haemodialysis treatment at St. Paul’s Hospital. Specifically, you are being asked provide consent to allow your nephrologist (a physician who specializes in the treatment of kidney failure) from St. Paul’s Hospital to access your medical records for purposes of collecting information to complete SORDS and the ESRD-SI.

You are also being asked to give your consent for a nurse to approach you to fill out two brief questionnaires. This may be done while you are dialyzing. One of these questionnaires will ask how you feel about your general physical health. The other will ask questions about your present mood. The questions may be read to you, if you wish, or you may complete the form yourself. In total, these questionnaires should take approximately 20 minutes to complete.

Because this information is being collected only for the purposes of research, it will not be used for treatment, nor will it be used to provide you with information of a clinical nature.

By participating in this study, you would be aiding the continuing efforts of physicians and scientists to improve treatment for renal failure and develop new and increasingly effective ways to prevent and treat psychological effects of renal failure and its treatment. While it cannot be guaranteed that the study will itself result in changes in the treatment of renal failure, this study represents an important first step towards accurately measuring the effects of kidney failure.

The information provided by you will be used for the purposes of completing a research project for a
doctoral degree in clinical psychology. Only group results will be reported. In other words, no individual scores or information about individuals participating in the study will be published in either the dissertation document or in documents submitted to scientific conferences or professional journals.

Confidentiality:
Your name will not appear on any of the information collected. Instead, a separate list of participant names will be removed from medical data and the questionnaires and will be kept in a locked drawer in the office of Dr. David A. Scott at the University of Saskatchewan. Only code numbers associated with participant names will appear on materials used in this research project. All information is confidential and will be kept at all times in a secure facility on the premises of the University of Saskatchewan for a minimum of five years.

Should you experience fatigue or emotional upset during any time that you are participating in this study, you may pause to rest until you feel able to continue, or withdraw from the study. You may inform the interviewer, and you will be provided with information regarding agencies that provide assistance to persons experiencing emotional distress. You will also be provided names of support personnel who may assist you with any emotional difficulties that arise during the interview process. You may discontinue the interview, or withdraw permission for any medical information previously gathered to be used for the purposes of this research at any time should you wish to do so. Such withdrawal from the study will in no way affect your treatment. Please note that your medical care is in no way dependent upon your participation in this study. Should any information come to light that could affect your decision to allow your medical files to be used in this study, you will be informed of this.

Should you have any questions or concerns regarding this study you may telephone the numbers listed below. If there are any changes to the study that may affect you or your decision to participate in the study, you will be notified by one of the investigators.

I, ___________________________, agree to allow my medical records to be used for the purposes of the above-named study. I agree to complete the surveys described in this letter. The study and the contents of this consent form have been explained to me. I understand the content of this form, and have been provided with a copy of the consent form for my own records.

Participant Signature: ___________________________

Researcher’s Signatures:

David A. Scott, PhD
Dissertation Supervisor
Associate Professor
Department of Psychology
University of Saskatchewan
Phone: 966-6673

Diana L.E. Alexander, Msc
Doctoral Candidate,
Clinical Psychology,
Department of Psychology
University of Saskatchewan
Phone: 966-6673 or 975-5425

George Pylypchuk, MD
Renal Unit
St. Paul’s Hospital

Office of Research Services
210 Kirk Hall, 117 Science Place
University of Saskatchewan, Saskatoon, Saskatchewan, S7N 5C8
Phone: 966-8576
Consent Form for Renal Patients Receiving Peritoneal Dialysis

An Investigation of the Validity and Reliability of the Severity of Renal Disease Scale (SORDS).

Researchers:
(1) David A. Scott, PhD  
Dissertation Supervisor  
Department of Psychology  
966-6673
(2) Diana L.E. Alexander, Msc  
Doctoral Student  
Department of Psychology  
966-6673 or 975-5425
(3) George Pylypchuk, MD  
Renal Unit  
St. Paul’s Hospital

Purpose and Objectives of the Study:
The study you are being asked to participate in involves the further development of a measure of how severely ill a person is. The measure, called SORDS (Severity of Renal Disease Scale) takes into account the presence or absence of a number of health problems sometimes involved with renal disease (disease of the kidneys). Information about these problems is taken from the medical file of each patient by their physician. It is expected that those patients experiencing more severe health problems will show higher scores on the SORDS scale.

Also as part of this study, we want to compare scores on SORDS with another measure of illness severity, the ESRD-SI (End-Stage Renal Disease - Severity Index). Scores on both SORDS and the ESRD-SI are based on available medical information from each patient’s file, and as they are completed by your physician, they do not require patient interviews. Lastly, we want to compare scores from both illness severity measures with scores from another survey of emotional health. If you choose to participate, you will be asked some questions about your present mood.

Consent:
The study you are participating in involves patients who are currently receiving peritoneal dialysis treatment. Specifically, you are being asked provide consent to allow your nephrologist (a physician who specializes in the treatment of kidney failure) from St. Paul’s Hospital to access your medical records for purposes of collecting information to complete SORDS and the ESRD-SI.

You are also being asked to give your consent for a nurse to approach you to fill out a brief questionnaire. This may be done while you are on the peritoneal dialysis unit. The questionnaire will ask you questions about your present mood. The questions may be read to you, if you wish, or you may complete the form yourself. In total, the questionnaire should take approximately 10 minutes to complete.

Because this information is being collected only for the purposes of research, it will not be used for treatment, nor will it be used to provide you with information of a clinical nature.

By participating in this study, you would be aiding the continuing efforts of physicians and scientists to improve treatment for renal failure and develop new and increasingly effective ways to prevent and treat psychological effects of renal failure and its treatment. While it cannot be guaranteed that the study will itself result in changes in the treatment of renal failure, this study represents an important first step towards accurately measuring the effects of kidney failure.

The information provided by you will be used for the purposes of completing a research project for a doctoral degree in clinical psychology. Only group results will be reported. In other words, no individual scores or information about individuals participating in the study will be published in
either the dissertation document or in documents submitted to scientific conferences or professional journals.

Confidentiality:
Your name will not appear on any of the information collected. Instead, a separate list of participant names will be removed from medical data and the questionnaires and will be kept in a locked drawer in the office of Dr. David A. Scott at the University of Saskatchewan. Only code numbers associated with participant names will appear on materials used in this research project. All information is confidential and will be kept at all times in a secure facility on the premises of the University of Saskatchewan for a minimum of five years.

Should you experience fatigue or emotional upset during any time that you are participating in this study, you may pause to rest until you feel able to continue, or withdraw from the study. You may inform the interviewer, and you will be provide you with information regarding agencies that provide assistance to persons experiencing emotional distress. You will also be provided names of support personnel who may assist you with any emotional difficulties that arise during the interview process. You may discontinue the interview, or withdraw permission for any medical information previously gathered to be used for the purposes of this research at any time should you wish to do so. Such withdrawal from the study will in no way affect your treatment. Please note that your medical care is in no way dependent upon your participation in this study. Should any information come to light that could affect your decision to allow your medical file to be used in this study, you will be informed of this.

Should you have any questions or concerns regarding this study you may telephone the numbers listed below. If there are any changes to the study that may affect you or your decision to participate in the study, you will be notified by one of the investigators.

I, __________________________ agree to allow my medical records to be used for the purposes of the the above-named study. I agree to complete the survey described in this letter. The study and the contents of this consent form have been explained to me. I understand the content of this form, and have been provided with a copy of the consent form for my own records.

Participant Signature: __________________________

Researcher’s Signatures:

David A. Scott, PhD
Dissertation Supervisor
Associate Professor
Department of Psychology
University of Saskatchewan
Phone: 966-6673

Diana L.E. Alexander, Msc
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Phone: 966-8576
APPENDIX F
Consent Form for Participant Group # 3
(Pre-dialysis patients)
Consent Form for Renal Patients Not Yet Requiring Dialysis

An Investigation of the Validity and Reliability of the Severity of Renal Disease Scale (SORDS).

Researchers:
(1) David A. Scott, PhD
    Dissertation Supervisor
    Department of Psychology
    966-6673
(2) Diana L.E. Alexander, MSc
    Doctoral Student
    Department of Psychology
    966-6673 or 975-5425
(3) George Pylypchuk, MD
    Renal Unit
    St. Paul’s Hospital

Purpose and Objectives of the Study:
The study you are being asked to participate in involves the further development of a measure of how severely ill a person is. The measure, called SORDS (Severity of Renal Disease Scale) takes into account the presence or absence of a number of health problems sometimes involved with renal disease (disease of the kidneys). Information about these problems is taken from the medical file of each patient by their physician. It is expected that those patients experiencing more severe health problems will show higher scores on the SORDS scale.

Also as part of this study, we want to compare scores on SORDS with another measure of illness severity, the ESRD-SI (End-Stage Renal Disease - Severity Index). Scores on both SORDS and the ESRD-SI are based on available medical information from each patient’s file, and as they are completed by your physician, they do not require patient interviews. Lastly, we want to compare scores from both illness severity measures with scores from other surveys of physical and emotional health. If you choose to participate, you will be asked some questions about how you feel about your present health status, and other questions about your present mood.

Consent:
The study you are participating in involves patients who are diagnosed with renal disease, including patients not yet requiring dialysis. Specifically, you are being asked provide consent to allow your nephrologist (a physician who specializes in the treatment of kidney failure) from St. Paul’s Hospital to access your medical records for purposes of collecting information to complete SORDS and the ESRD-SI.

You are also being asked to give your consent to be approached and asked to fill out two brief questionnaires. One of these questionnaires will ask how you feel about your general physical health. The other will ask questions about your present mood. The questions may be read to you, if you wish, or you may complete the form yourself. In total, these questionnaires should take approximately 20 minutes to complete.

Because this information is being collected only for the purposes of research, it will not be used for treatment, nor will it be used to provide you with information of a clinical nature.

By participating in this study, you would be aiding the continuing efforts of physicians and scientists to improve treatment for renal failure and develop new and increasingly effective ways to prevent and treat psychological effects of renal failure and its treatment. While it cannot be guaranteed that the study will itself result in changes in the treatment of renal failure, this study represents an important first step towards accurately measuring the effects of kidney failure.

The information provided by you will be used for the purposes of completing a research project for a
doctoral degree in clinical psychology. Only group results will be reported. In other words, no individual scores or information about individuals participating in the study will be published in either the dissertation document or in documents submitted to scientific conferences or professional journals.

Confidentiality:
Your name will not appear on any of the information collected. Instead, a separate list of participant names will be removed from medical data and the questionnaires and will be kept in a locked drawer in the office of Dr. David A. Scott at the University of Saskatchewan. Only code numbers associated with participant names will appear on materials used in this research project. All information is confidential and will be kept at all times in a secure facility on the premises of the University of Saskatchewan for a minimum of five years.

Should you experience fatigue or emotional upset during any time that you are participating in this study, you may pause to rest until you feel able to continue, or withdraw from the study. You may inform the interviewer, and you will be provided with information regarding agencies that provide assistance to persons experiencing emotional distress. You will also be provided names of support personnel who may assist you with any emotional difficulties that arise during the interview process. You may discontinue the interview, or withdraw permission for any medical information previously gathered to be used for the purposes of this research at any time should you wish to do so. Such withdrawal from the study will in no way affect your treatment. Please note that your medical care is in no way dependent upon your participation in this study. Should any information come to light that could affect your decision to allow your medical files to be used in this study, you will be informed of this.

Should you have any questions or concerns regarding this study you may telephone the numbers listed below. If there are any changes to the study that may affect you or your decision to participate in the study, you will be notified by one of the investigators.

I, ______________________________ agree to allow my medical records to be used for the purposes of the above-named study. I agree to complete the surveys described in this letter. The study and the contents of this consent form have been explained to me. I understand the content of this form, and have been provided with a copy of the consent form for my own records.

Participant Signature: ______________________________

Researcher’s Signatures:

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