





Adjustment to End Stage Renal Failure (ESRF) has been the topic of a vast number of studies, however a clear picture of adjustment and the process of adjustment has yet to

**THE CONCEPTUALISATIONS OF ADJUSTMENT IN PATIENTS WITH END STAGE RENAL FAILURE, THEIR CARERS/RELATIVES AND NURSING STAFF**

renal dialysis nursing staff, involved in their care, were also interviewed. The findings of this study indicated that the key process in adjustment was 'Taking on board a new approach to being and living'. This process involved participants accepting their illness as a cognitive and affective level, in addition to making illness into their identity. Four other processes identified were the above, Getting back to life, Making arrangements to accommodate illness and Coping skills and Experiencing losses. These conceptualised the social, emotional and cognitive facets of adjustment. Implications for theory, practice and research are discussed.

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ABSTRACT

Adjustment to End Stage Renal Failure (ESRF) has been the topic of a vast number of studies, however a clear picture of adjustment and the process of adjustment has yet to emerge. The purpose of this Grounded Theory study was to investigate the conceptualisations of adjustment of patients with ESRF. A sample of ten subjects with ESRF were interviewed, five of which had been receiving treatment for ESRF for six weeks and five for twelve months. In addition, six of the patients' partners/relatives and three home dialysis nursing staff, involved in their care, were also interviewed. The findings of this study indicated that the key process in adjustment was 'Taking on board a new approach to being and living'. This process involved participants accepting their illness at a cognitive and affective level, in addition to integrating illness into their identity. Four other processes subsumed under the above key process, namely, Getting back to life, Making adaptations to accommodate illness and treatment, Coping skills and Experiencing losses. These encapsulated the social, emotional, behavioural and cognitive facets of adjustment. Implications for theory, health care practice and future research are discussed.

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## ACKNOWLEDGEMENTS

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### END STAGE RENAL DISEASE AND ITS TREATMENT

ESRD is the end stage of various stages of a number of disease processes affecting the kidney. The most commonly defined by an irreversible 90-95% reduction in kidney function. It can occur suddenly as a complication of trauma or from a rapidly progressing kidney disease. Alternatively, ESRD can be the result of a progressive and often prolonged renal failure caused by a variety of chronic diseases or conditions, such as glomerulonephritis, diabetes, high blood pressure and systemic diseases such as proteinuria, haematuria, etc. In the latter case, patients' renal function is diminished over time and they may need for treatment after 10 years may be required. There may be no specific treatment for the renal disease, although this is not always the case. There is also a need for management of medication given.

The decision to begin treating a patient with some form of renal replacement therapy is made a clinical one, based on the amount of serum creatinine in the blood, as it is based on the symptoms experienced by the patient.

## INTRODUCTION

### 1.0 PREFACE

This section will begin by describing End Stage Renal Failure (ESRF) and its treatment. It will then review some of the studies that have looked at adjustment to ESRF and discuss some of their inherent problems. Research focusing on adjustment to chronic illness in general will then be considered and finally the research questions will be proposed.

### 1.1 END STAGE RENAL FAILURE AND ITS TREATMENT

ESRF is the term used to describe the end point of a number of disease processes affecting the kidneys. The onset is usually defined by an irreversible 90-95% reduction in kidney function. It can occur suddenly as a complication of trauma or from a rapidly progressive kidney disease. Alternatively, ESRF can be the result of a progressive and often prolonged renal failure caused by a variety of chronic diseases or conditions, such as glomerulonephritis, diabetes, high blood pressure and genetic disorders such as polycystic kidneys. In the latter case, patients' renal function is monitored, sometimes for years, until the need for treatment arises. There may be no uraemic symptoms during this monitoring stage, although this is not always the case. There is also no medical management or medication given.

The decision to begin treating a patient with some form of renal replacement therapy is either a clinical one, based on the amount of serum creatinine in the blood, or it is based on the symptoms experienced by the patient.

There are three main forms of renal replacement therapies available: Hemodialysis (HD), Peritoneal Dialysis and transplant. Each of these will be considered below. In HD waste products are removed from the blood by an external artificial kidney machine. This is done three times a week for between four to eight hours at a time. The patient either attends hospital or has a machine in his/her home. Along with this the patient has to take medication, follow a stringent diet, and restrict his/her fluid intake.

Peritoneal dialysis, in contrast to HD is performed within the patient's body. A dialysate (finely balanced salt solution) is introduced into the abdominal cavity from a plastic bag via a permanently placed catheter. The solution is then left in the cavity for a couple of hours before being drained thereby removing waste products from the blood via the processes of osmosis and diffusion. The most common form of peritoneal dialysis is continuous ambulatory peritoneal dialysis (CAPD) which can involve four dialysate bag changes (exchanges) a day. As with HD the patients will have a series of medications and dietary restrictions but these are not nearly as strict. Also as this is performed by patients, there is no need for them to attend the hospital although initially they will attend for one week for an intensive training in CAPD. Not only do patients have to learn the procedure but also must be cognizant of both the conditions under which the procedure takes place (where sterility must be maintained) as well as the somatic changes that may occur, like for example the early recognition of infection (Christensen *et al.*, 1994).

Kidney transplantation is also an option although it is not a permanent solution to ESRF, infact kidney transplantations rarely last longer than five to ten years. It is considered a treatment because medications such as immunosuppressants must be taken after surgery to reduce the likelihood of graft rejection (Binik *et al.*, 1993).

Once patients reach ESRF they are given a choice of treatment between HD and CAPD. However in reality, in Leicester, patients are strongly encouraged to use CAPD as their treatment choice. This is because it is considered to give patients more freedom, the patient is able to have active responsibility for his/her own care and it is also less expensive than hospital based HD. Patients are also placed on the transplant list if they meet certain criteria, however the demand for kidneys far outweighs the availability.

ESRF and its treatment is considered to be highly stressful (Will and Johnson 1994). The dialysis patient has to cope with, amongst other things, the constant threat of death, a reduced life expectancy, a decrease in physical strength and an intrusive regime. However the outlook has improved for dialysis patients in the last few years. Life expectancy has increased as have patients' quality of life. This has been helped by the availability of recombinant erythropoietin (EPO), which corrects anaemia (Renal patients suffer loss of energy and fatigue as a result of a deficiency in endogenous erythropoietin, a hormone responsible for maintaining normal red blood cells).

As in other chronic illnesses a great deal of psychological and psychiatric research has focused on exploring issues surrounding adjustment to ESRF. Generally three types of study can be identified, prevalence studies, studies examining factors that affect adjustment and studies exploring the process of adjustment. These studies will now be discussed followed by a consideration of their inherent problems.

## **1.2 PREVALENCE STUDIES**

Early studies purporting to explore adjustment to ESRF focused on finding out the prevalence of what they considered to be indicators of adjustment or maladjustment. For example the incidence of vocational adjustment (returning to work and having a productive

life outside dialysis), depression and compliance (with the dietary and fluid restrictions and medication) were all used as a measure of adjustment.

It is remarkable how studies have differed in their findings. For example rates of vocational adjustment have varied from 28% to 51% (Kaplan De Nour, 1982). Incidence of depression have ranged from 1% to 50% and “non-compliance” from 15% to 93% (Levenson and Glocheski 1991). There are several reasons for these inconsistencies, Levenson and Glocheski (1991) point out that some investigators have assessed patients in the early course of their dialysis, while others have assessed their group of patients later on in their treatment. This is important because depression in particular has been found to vary over the course of ESRF treatment. Also, in terms of the prevalence of psychopathology, studies have varied where some have assessed life time history and others have measured the point prevalence of psychiatric disorders. Other studies have made no attempt to standardise in relation to onset of ESRF, such lack of standardisation can lead to prevalence-incidence bias (Levenson *et al.*, 1991).

Different criteria for assessing patients' adjustment to ESRF have also been used. A study conducted by Smith *et al.*, (1985) highlighted this problem. They assessed a group of patients using three measures of depression and found that on the Beck Depression Inventory (BDI), 47% of their patients were classified as depressed, on the Multiple Affect Adjective Checklist 10% were depressed and when DSM III criteria were used, 5% were classified as depressed. Thus if studies use different definitions and criteria for depression the rates will vary dramatically. In summary, despite there being a large number of prevalence studies carried out, the picture emerging is far from clear (Kaplan De Nour 1982).

### **1.3 FACTORS AFFECTING ADJUSTMENT TO ESRF.**

Other studies have looked at what factors affect adjustment to ESRF, again, as these are described, it will be seen that different measures of adjustment have been used.

#### **1.3.1 CONTROL AND ITS EFFECT ON ADJUSTMENT**

Some researchers have explored the relationship between perceived control, that is the extent to which a person believes they have control over their health, and its effect on adjustment to ESRF. Control has already been shown to be related to positive adjustment for patients who have other chronic illnesses (Afflect *et al.*, 1987). Poll and Kaplan De Nour (1980) studied the relationship between locus of control and three aspects of adjustment; vocational adjustment, compliance and acceptance of illness. They found that people who had an external locus of control (belief that external factors are involved in health) were less well adjusted on all the measures used than those who had an internal locus of control. Similar results have also been reported by Christenden *et al.*, (1991) and Wittenberg *et al.*, (1983) who found a positive relationship between perceived control, adaptive coping and various psychosocial adjustment measures.

Other studies have explored the relationship between actual control or behavioural control over treatment and adjustment. These studies have commonly classified patients on hospital based HD to have low control, patients on HD at home to have medium control and patients on CAPD to have high control over treatment. The reasons for this are evident from the descriptions above of the treatment procedures. Devins *et al.*, (1981) used these criteria and the BDI as the measure of adjustment. They found that there was no relationship between behavioural control and depression. Several other studies, such as those conducted by Sacks *et al.*, (1981) and by Devins *et al.*, (1982), albeit using

different measures of psychosocial adjustment, also did not find a relationship. These studies challenge the commonly held view in the medical profession that CAPD patients who control their treatment are better adjusted (Eitel *et al.*, 1995).

Eitel *et al.*, (1995), further explored the relationship between behavioural control and adjustment. They predicted that as illness severity increases, the burden of controlling one's treatment, as in CAPD, would increase depression. It would be higher in people whose illness was more severe. As a result they hypothesised that increased disease severity would produce a concomitant increase in depression in CAPD patients but not for hospital treated HD patients. Adjustment was measured using the BDI and Eitel *et al.*'s (1995) hypothesis was confirmed. As the severity of the disease increased, 'high control' CAPD patients reported higher levels of depression than did less severely ill CAPD patients and low control HD patients. Thus it seems that it is only when illness poses a serious threat to the individual does control over treatment affect adjustment.

The findings of Eitel *et al.*, (1995) are also consistent with research into other chronic illnesses that suggest that control over illnesses can become a burden because patients can view this control as an added responsibility and feel they are blameable for negative events. Eitel *et al.*, (1995) also found that this relationship between control and depression was reduced to a non significant level when the results from a scale measuring illness intrusiveness (the extent to which illness intrudes into various areas of life) were taken into account. Specifically it was found that the way the illness intruded into social relations was responsible for the increase in depression. In addition subjects reported that others did not understand how seriously ill they were. Various explanations were offered by Eitel *et al.*, (1995) to account for these findings. They postulated that for patients using CAPD, treatment is not separate from their home lives whereas for HD patients treatment is only

conducted at hospital sites. As the illness becomes more severe it may have been difficult for CAPD patients to quell distressing thoughts about the illness as it increasingly encroached and intruded into their daily life.

An alternative explanation for their findings is that medical staff may assume, as previous literature has suggested, home (CAPD) patients are healthier and better adjusted than their HD counterparts. These attitudes may manifest themselves in increased expectations of these patients. When such patients become more severely ill and burdened with their own care they may not be given the same support as patients on HD.

There are a number of limitations to this study, including that only one component of the data actually came from the patients, the majority was recorded by consultants and nurses.

### **1.3.2 FAMILY AND MEDICAL/PROFESSIONAL STAFF INFLUENCES ON ADJUSTMENT**

A more recent study by Hatchett *et al.*, (1996) has expanded on the findings of Eitel *et al.*, (1995), that patients felt they were not well understood by others. Hatchett *et al.*, (1996) assessed patients perceptions of the demands and expectations that family and medical staff placed on them in relation to their responsibility for everyday routine functions and medical care. These expectations were measured at two points over a period of two months.

Scales measuring depression, hopelessness, satisfaction and quality of life were also used as indicators of adjustment. They found that discrepant expectations on the patients' part predicted subsequent decreases in adjustment. In addition, the alternative hypothesis that those who were poorly adjusted would come to misperceive the expectations of others was not supported. Hatchett *et al.*, (1996) concluded that modifying interpersonal expectations between families and patients may help to improve adjustment.

A few studies have further explored the role of the family in determining adjustment. For example, Czackes *et al.*, (1978) (cited by Armstrong 1978) and Abram, (1970) have shown that there is a correlation between social support provided by family members and a patient's adjustment to dialysis. Pentacost, (1970) found that there was a strong positive relationship between resolute communications from family members of warmth, acceptance and positive regard and staff ratings of patients' adjustment. However, generally adjustment related studies have not incorporated family factors as a variable.

Some studies have reported the influence of staff-patient relationships on patients' adjustment. Blodgett (1982) cites a study by Foster and McKegney (1978) in which they explored the relationship between the complex dynamics of staff and patients and survival in patients. They found that over time the relationship between staff and patients influenced not only adjustment but their survival. For example, in a group of patients designated by staff as "bad", 7 deaths occurred in 2 years as opposed to none in the group staff saw as 'good' patients. The authors point to the psychoanalytic process of splitting as a significant element in the group behaviour of staff and patients.

In a similar vein Kaplan De Nour *et al.*, (1974) explored the relationship between nephrologists' emotional reactions to hemodialysis and patients' adjustment. The researchers began by investigating the nephrologists criteria for assessing adjustment in their patients because they had found, in their clinical practice, that their assessment could be very different. They found that some nephrologists used compliance to diet, functioning at work and emotional condition as their measurement of adjustment whereas others used single factors such as behaviour on dialysis. Most of them over estimated their patients' adjustment (compared to the assessments carried out by the researchers). It was concluded that the nephrologists were using denial. Furthermore there was a tendency for

patients to do better in units where less denial was used by the nephrologists in charge. The authors were “inclined to believe” that it was the physicians’ use of denial, presumably because they found the situation stressful, that was the causative factor in the patients’ adjustment because they found that they had high expectations of how patients should deal with and react to treatment. However, this needs to be investigated further.

### **1.3.3 PATIENT FACTORS IN ADJUSTMENT**

Other studies have looked at denial in renal patients and its relationship with adjustment. Fricchione *et al.*, (1992), for example, used a quantitative rating scale to explore denial (the denial scale is thought to measure avoidance -a persons refusal to talk about a threat (Lazarus 1989 cited by Fricchione *et al.*, (1992),) and a range of scales to measure adjustment including the symptom Checklist 90 (revised), a client satisfaction scale and a psychiatric rating scale. Between subjects there was no difference between medical - surgical history, duration of illness or morbidity. They found find that patients with low denial were more likely to have greater interpersonal sensitivity (low self esteem) and greater mood and sleep disturbance than high deniers. However these results should be treated with caution because the sample size was small.

Some studies have explored age as a factor affecting adjustment. It was commonly felt that older patients have greater adjustment problems and poorer survival as compared to their younger counterparts (Blodgett, 1982). However, findings have been contradictory, for example Walker *et al.*, (1976) found that over a three year period the level of survival was equivalent between patient groups above and below fifty years old. Furthermore the older patients were better on the self care procedures, when compared to the younger group, “because of their greater dependability and maturity”.

In contrast other studies have found that survival decreases after the age of thirty five.

Lowenhaupt (1977) (cited by Blodgett 1982), found that older patients were, as a group, more susceptible to emotional problems, secondary to chronic renal failure.

Blodgett concludes that in general the literature has failed to demonstrate age as a major influence on adjustment. He also points out that survival and adjustment whilst related are not synonymous. Thus the increasing emphasis has been on quality of life which is different to quantity i.e. the length of survival.

#### **1.3.4 ILLNESS FACTORS AND ADJUSTMENT**

Blackburn *et al.*, (1982) looked at the effects of having multiple illnesses on adjustment to ESRF. They used the locus of control and depression scales to look at the differences in adjustment between a group of people who had both diabetes and ESRF and those with only ESRF. Initially they found that the diabetic group treated the onset of ESRF and HD as a crisis. However, following on from this they adapted relatively quickly, when compared to the non diabetic group, who tended to deny the severity of their condition thereby delaying the adaptive process.

Illness intrusiveness (illness induced disruptions to activities and interests) has been hypothesised to influence adjustment to illness in two interrelated ways. One involves the decrease in positively rewarding experiences as activities are no longer undertaken (Devins 1994, Devins *et al.*, 1992) and the other involves the reduced perception of personal control which results in limiting an individual's ability to procure positively valued outcomes (Devins *et al.*, 1982).

As have been discussed here a number of factors have been investigated in an attempt to study their effect on adjustment to ESRF. However, it is difficult to draw conclusions for

a unifying theory on adjustment from these because studies have varied enormously in the conceptualisation and measurement of adjustment they have adopted.

### **1.3.5 THE PROCESS OF ADJUSTMENT**

Levy and Reichman (1972) are some of the only researchers who have explored the process of adjustment and adaptation to ESRF. Using their own interview format, they assessed patients' affects, defences, life events and coping strategies over a three year period. They identified three distinctive stages of adaptation. Firstly there was a honeymoon period in which patients had just begun HD treatment and experienced physical and emotional improvements. The second phase classified as the period of disenchantment and discouragement, was where the patient began to realise how many adjustments he/she needed to make in order to attempt to resume his/her past life. Feelings of helplessness and sadness were the dominant affects at this time. Lastly there was a period of long term adjustment where the patient gradually learnt to accept their limitations and their illness. This period was characterised by fluctuations in emotional and physical state, but in the main there was a feeling of contentment. The actual usefulness of these stages in research has yet to be determined, but as Blodgett (1982) notes these stages would seem useful in helping provide some order in an otherwise chaotic type of illness.

Levy and Reichman's (1972) findings suggest that there is an increasingly optimistic progression in the adjustment process, however other research would refute this. For example, Shea (1965) found that with increasing time patients became less tolerant of the treatment and Blakely (1977) found that death anxiety increased with the amount of time the patient had to undergo treatment.

## 1.4 PROBLEMS IN THE STUDIES EXPLORING ADJUSTMENT TO ESRF

One of the main problems with the studies on adjustment to ESRF seems to be that adjustment has never been formally defined. Studies have thus tended to look at single dimensional issues, thereby studying aspects of adjustment in isolation from the fabric of a patient's life. This has consequently lead to a plethora of studies which have generated inconsistent results. We seem to have only limited information about some aspects of adjustment (e.g. compliance, social activities) and have contradictory information from other studies looking at the prevalence of depression and the return to work.

Blodgett (1982) points out that what has actually been meant by adjustment has been left to the norms and assumptions of the individual treatment staff. As has already been previously stated, he notes that this failure to consistently or adequately define adjustment is a major criticism of the dialysis literature.

Blodgett (1982) also makes a second point that underlying much of the adjustment literature is an assumption of patients' psychopathology. Thus patients are compared to standards and norms rather than in terms of their particular situation and context and qualities. An implication of this is that people are labelled in terms of their disabilities rather than their capabilities. The pathology is then seen in every aspect of the individual.

Blodgett (1982) argues that this has lead studies to view the major goal for patients to be physical well being. Thus the first priority is compliance with the treatment regime and social and emotional issues are adjunct only in so far as they may affect compliance. Many early studies in particular seem to be consistent with this view point. Fortunately things are changing and there is growing interest in social and psychological functioning.

Another problem with studies examining adjustment to ESRF is the paucity of research looking at psychological interventions to help improve patient care and adjustment to

ESRF. Symister and Friend (1996) report that the few studies that have been conducted are mainly case studies reporting on improving compliance to fluid restrictions.

Methodological problems also hamper many studies. For example some have failed to control for demographic factors, treatment modalities, time point in treatment, aetiology of renal failure, comorbidity, severity of illness and the length of time in treatment as important factors in adjustment. Blodgett (1982) states 'it is a major interpretative restriction of the entire literature that time in treatment has received so little attention'.

In summary, a major criticism of the literature on adjustment to ESRF is that adjustment has never been defined and this has led to studies that have firstly employed vastly different measures of adjustment and secondly studies that have used single dimensional measurements. Both have limited the findings and comparability of results. Thus despite a vast amount of research being conducted we still do not have a clear picture of how people adjust to ESRF. This lack of clarity may also be the reason why there is a dearth of intervention studies on improving a patient's adjustment.

The literature on adjustment to chronic illness in general will now be considered to see if it can provide any useful framework.

### **1.5 WHAT IS ADJUSTMENT ?**

It would appear that there are very few published articles/literature on adjustment per se. Of those that have been written, they have tended to identify salient issues in adjustment to chronic illness, but a theoretical conceptualisation is lacking. Furthermore they have mainly been sociological studies. For example Hyman (1975) discussed the dependency conflict inherent in people with chronic illnesses, that is adopting the dependency role when the peoples' capacities are only reduced, not eliminated. Davis (1978) equated adjustment

to illness as adjustment to stigmatisation and part of the adjustment process involved individuals acquiring skills in “deviance disavowal”.

The psychological literature also lacks a conceptualisation of adjustment. Wright (1991) notes that instead, conceptualisations have been drawn from two sources. Firstly, adjustment has been conceptualised as the most adaptable end product or outcome of the process of coping. For example Moos and Tsu (1977) in their work examining how people respond to the crisis of physical illness, have distinguished seven adaptive tasks. Three of these are illness related and include: dealing with pain and incapacitation, dealing with hospital environment and treatment procedures and developing relationships with medical and professional staff involved in their care. The other four are more general and include preserving an adequate emotional balance by managing upsetting feelings generated by the illness, preserving a satisfactory self image; preserving relationships with friends and family, and preparing for an uncertain future.

In a similar vein to Moos and Tsu (1977), Weissman (1972) described adjustment as those behaviours whose outcome leads to survival, competent behaviour and responsible conduct. This was defined in relation to terminal illness but generalises to other chronic illnesses.

Finally Wright (1991) in his conceptualisation of adjustment, has distinguished between primary and higher order coping outcomes. The former includes acceptance of illness, adaptation to illness and adherence. The latter includes subjective well being, illness status and self perceived health status. In his conceptualisation the primary outcomes are directly related to the illness with acceptance and adaptation representing affective and behavioural components respectively. He states that higher order outcomes may not entirely be related to illness. He sees adjustment as an aggregation of acceptance, adaptation and adherence.

The second source of conceptualising adjustment identified by Wright (1991), and one which has been used by the studies mentioned above, involves operationalising the adjustment construct by, for example, specially designed inventories such as the Acceptance of Illness Scale (AIS) (Felton and Revenson 1984), the Psychosocial adjustment to illness scale (PAIS) (Morrow *et al.*, 1978), or using a mixture of measures. Wright (1991) states that the problem with many of these is that they tend to explore higher order outcomes and thus tell us little about the processes involved in adjustment. The AIS, however, is designed specifically so that it is not measuring outcomes such as mood or social functioning.

In summary there is only a limited amount of literature that actually provides a theoretical framework in which to understand adjustment to chronic illness.

## **1.6 RESEARCH QUESTIONS AND AIMS OF THIS RESEARCH**

The question of how people adjust to ESRF and the process of this adjustment is still a topic that warrants further investigation. What seems a pertinent question, and one that has driven this research, is what does good adjustment mean to patients and how does this differ to the view of others such as professionals who work with them.

The aim of this research is thus to explore the conceptualisations of ‘adjustment to illness’ in a group of patients who have ESRF. Views of the patients’ carers/partners and named nurses will also be important to elicit in order to contrast and compare with the patients.

It was felt that qualitative methods would be the tailored choice for this research because such methods are designed to be used in subject areas that are poorly conceptualised.

Specifically the Grounded Theory method is explicitly aimed at developing theoretical concepts that are grounded in the data that has been collected. Qualitative methods will be

discussed in more detail in the next section. However in keeping with this approach a number of research questions will be proposed as opposed to a set of hypotheses.

The following research questions were identified:

- 1) How do people who have ESRF conceptualise 'adjustment to illness'?
- 2) How do their general views about adjustment and their feelings about whether they have adjusted compare and contrast with those of their relatives and named nurses?

Stemming from this a number of other questions also arose and these include:-

Do views about adjustment change over time?

How useful or relevant is the recently developed AIS scale ( unique in its claims to solely measure adjustment). Do scores on this instrument correlate with subjective reportings and do subjects think the questions are relevant?

Is perceived illness intrusiveness, a commonly used concept in adjustment studies, an important factor in adjustment? The Illness Intrusiveness Scale (IIRS) (Devins *et al.*, 1983) will be used to explore this.

Thus the major aim of this study is to provide a theoretical framework with which to understand adjustment to ESRF.

## METHODOLOGY

### 2.0 PREFACE

The discipline of Psychology is changing, empirical studies are now embracing different kinds of methodologies that are no longer based on the traditional positivist, experimental design.

It is thought that this shift has occurred because of a growing discontentment with the “narrowness of psychology”, with its emphasis on the experimental design, statistical analysis and an epistemology based on the natural sciences (Smith 1995). This move to a more naturalistic psychology has manifested itself at a number of different levels. For example it has opened up the areas of study that were previously neglected, such as the self. It has also opened up the type of data analysed i.e. diary, self reports, although Smith (1995) argues that the quantitative paradigm has still dictated the form in which the data has been analysed and collected.

More recently, qualitative methods, traditionally the tools of the social scientist, have caught the attention of psychologists and are increasingly being utilised by them. The first part of this section will explore in more detail the qualitative paradigm and the reasons why it has been utilised in this research. The second part of the section will report on data collection and procedures.

### 2.1 WHAT IS QUALITATIVE RESEARCH?

Qualitative research is a term used to describe a group of research methods that produces findings, not arrived at by the use of statistical analysis. The goal of qualitative research is

to develop concepts to gain understanding of complex psychological phenomena, with emphasis on the meanings and experiences of participants.

The qualitative paradigm is based on a different epistemological position than that of quantitative research, that of constructivism. Generally, meanings of both lay and scientific knowledge of the world are seen to not merely reflect the world as it exists but are constructed by persons within cultural, social and historical relationships (Henwood and Nicolson 1995). The emphasis of qualitative research focuses on gathering data that is non numerical because it allows the researcher to explore, and be sensitive to, multiple interpretations and meaning that drive thought and behaviour. In contrast the quantitative research paradigm (empiricism) is based on the natural sciences. It rests on positivist assumptions that the world is predictable, that there is an external objectifiable reality that can be measured through the testing out of hypotheses against phenomena. In the qualitative paradigm there is no assumption of objective reality but a range of different perspectives on various phenomena, with each person's perspective being valid.

Qualitative research is also held to be inductive, that is, it begins with an observation then moves towards hypothesis and theory. Quantitative approaches are generally concerned with testing hypotheses that arise from existing theory and are thus deductive. The researcher already decides in advance what constitutes the required data (Charmaz 1990). For this reason in an area where little theoretical knowledge has been developed qualitative methods can be invaluable.

## **2.2 QUANTITATIVE VERSUS QUALITATIVE APPROACHES?**

There has been a long standing debate concerning the relative virtues of qualitative and quantitative methods. As a consequence the two approaches have unfortunately been set

up in opposition to each other. This does nothing to encourage movement or interaction between the two methods or help to expand our understanding of them (Pope and May 1995). Both methods have their uses and can even be combined to help deepen analysis of a particular area.

Qualitative research is useful for 1) theory generation; where theory or measures are incomplete or non-existent or old paradigms have become obsolete; 2) for grounding analyses in participants' own experiences, accounts and worlds.

Quantitative research methods however are more appropriate for researching well understood phenomena, or well delineated constructs.

Good qualitative research is often considered to be a prerequisite for good quantitative work because until you classify you cannot quantify (Pope and May 1995). However good Qualitative methods can stand on their own not just as initiators of quantitative research.

### **2.3 PRODUCING GOOD QUALITY OF RESEARCH**

Authors have pointed out that qualitative research needs to be evaluated differently to quantitative (Henwood and Pidgeon 1992). Traditional criteria rest on the norm of objectivity, which assumes independence of the knower and the known. Therefore the overriding emphasis is on limiting researcher bias. However, the naturalistic paradigm challenges that dualistic distinction between knower and known, thus leading to the conclusion that the personal is always existing in research. (Stanley and Wise, 1983 cited by Henwood and Pidgeon 1992). The upshot of this is that criteria for judging the quality of research cannot rest on attempts at eliminating observer bias. With objectivity questioned the issue of how to judge qualitative research still remains. While there is no

methodological criteria that can, for certain, guarantee the absolute accuracy of research, several researchers have suggested a number of good practices that can both direct the research and help to evaluate it (Henwood and Pidgeon 1992). These include:-

**Keeping close to the data-** Categories produced should fit the data well. Turner (1981) recommends writing comprehensive definitions summarising why phenomena have been labelled in certain ways.

**Reflexivity-** Naturalistic research acknowledges and accepts the role of the researcher in the research process and advocates that this should be highlighted and revealed in the study.

Data should not be forced into pre-existing codes, but where prior concepts are used this should be stated.

**Presentation-**Presenting evidence in a form that enables independent interpretation by others (Fitzpatrick and Boulton 1994 cited by Rennie *et al.*, 1988). Raw data can be presented in the findings to support and illustrate any category so that the reader can judge for themselves whether they fit the data.

**Respondent validity-**This involves the researcher presenting and verifying their findings to the participants in the study. This is a contentious approach for a number of reasons including the argument that validity claims cannot only be based upon appeals to the correspondence between the researcher's accounts and the participants' experiences. Also research has highlighted the unavoidable power relations /role of discourses and ideological systems in influencing both respondents' outlooks and researchers.

## **2.4 THE QUALITATIVE APPROACH IN THIS STUDY**

A qualitative approach to research is the appropriate choice for this study for various reasons already mentioned in section 2.2. This study aims to explore an area of human psychology that is poorly conceptualised. In addition, the literature on adjustment to ESRF has lacked a theoretical definition, as has the adjustment literature in general.

Consequently there is a need to classify rather than quantify.

The symbolic interactionist school of thought, along with phenomenological ideas have chiefly been the positions that have guided the assumptions underlying this study.

Symbolic interactionists focus on the meanings of events to people and the symbols they use to convey these meanings. These meanings are derived from shared interactions which occur through the vehicle of language. Meanings are continually being revised in social interaction thus a symbolic interactionist position is dynamic and process driven.

Phenomenology is concerned with the study of objects of consciousness, thus it promotes the study of emotions. Within this context the generation of theory will undoubtedly be influenced by the researcher's own perspective.

For this research, a Grounded Theory approach has been used mainly because it provides explicit skills and techniques that help in the generation of theory.

## **2.5 GROUNDED THEORY**

Grounded Theory is a qualitative method, it emerged from the work of Strauss and Glaser in the 1960's. The Grounded Theory method consists of a set of inductive strategies for analysing data. These strategies include:

- 1) Generating low level categories from the data which closely fit the data.

2) Creating increasingly more abstract categories and analysing the relationship between these.

3) Making 'constant comparisons' between and within cases and categories to examine complexities.

4) Using the emerging theoretical categories to shape the data collection. Thus the researcher collects new data to check and fill out and extend theoretical categories.

The research is cyclical in nature as original data is compared with theory and theory with subsequent emerging themes to ensure 'goodness of fit'.

Grounded Theory can begin with general research questions, rather than pre-determined hypotheses. The questions may change as the research progresses depending on the developing findings. The strategies above can produce rich, dense data and elaborated categories (Charmaz 1990). The strategies do not produce statistical verifiable results requiring random sampling.

Although the goal of Grounded Theory is to build comprehensive theoretical systems, Charmaz (1995) has stated that most Grounded Theory works are still at the stage of developing clear categories by which to explicate processes in the worlds that they study, rather than producing tight theories which generate testable hypotheses. This would also seem a more realistic goal for this piece of research.

Grounded Theory has been criticised because of its apparent positivist underpinnings. On the one hand it is vindicated that the researcher approaches data with no preconceived ideas but on the other hand the researcher is also encouraged in the creative and interpretative process of generating new theory from qualitative data. Glaser and Strauss have, in effect, not addressed this issue so the role of the researcher remains largely an enigma. However Charmaz (1990) has advocated a constructivist version of grounded Theory which clarifies

how qualitative researchers must have a perspective from which they build their analyses, but without just applying it to new data or problems (Henwood and Pidgeon 1995). The researcher perspective includes substantive interests that will guide the data, schools of thought that the researcher is versed in, personal experiences and values. As mentioned above this is the assumption underlying this study. However Grounded Theory helps to keep the researcher focused on the analytic task, while also highlighting to the researcher to be aware of simply forcing pre existing ideas on the data.

## **2.6 DATA COLLECTION**

Nineteen people participated in this study. Ten of these participants were using CAPD as their dialysis treatment. Of these five had been on CAPD for twelve months and five for six to eight weeks. Four were women and six were men, equally distributed in the two groups (thus the gender ratio reflected the ESRF population as a whole). Their mean age was 56.3 years (range 47-66).

Five of the participants were the partners and one was the relative of the participants on CAPD.

Three of the participants were home dialysis nurses who were involved in the care of the participants on CAPD. This care involves visiting the participants several times in the first month after training and then conducting follow ups intermittently.

All but one CAPD participant met the pre-set selection criteria for this study. It was not known before the interview was arranged that this was the case. The participant in question was thus not included in the analysis of this study.

The selection criteria were designed to recruit an homogeneous sample of ESRF patients.

Thus all participants were on CAPD (the treatment choice at the Leicester General

Hospital). All were aged between 45-66 which is as near to the mean age of the ESRF population. The gender ratio reflected the ESRF population as a whole (1 to 3 females to males respectively). In order to explore length of time on treatment participants had either been on CAPD for six to eight weeks or 12 months.

Interviews for participants on CAPD were conducted in their homes. It was felt that this would help to make them feel relaxed and distance them from the medical setting. The interview lasted between one and one and a half hours. Relatives/partners were also interviewed at home. The interviews were conducted separately and were shorter in length. The nurses were also interviewed separately, in their office.

## **2.7 SELECTION/RECRUITMENT OF PARTICIPANTS.**

Home dialysis nurses were contacted to help suggest potential participants who met the selection criteria. The names were then passed on to the consultant for verification.

Potential participants and their relatives/partners were sent information and consent forms from the consultant and the interviewer. They were then contacted by phone directly by the interviewer. All the CAPD participants telephoned, agreed to participate in this study. Six of the partners/relatives agreed to participate. One refused, upon the researchers arrival for the interview. He stated that it was “really his wife’s problem”.

## **2.8 RESEARCH DESIGN**

For reasons already discussed above this study followed a Grounded Theory approach. Thus the research design was a cyclical process in which data collection and analysis were interwoven. However, for the purpose of simplification the procedures employed during the course of this study will be described as a series of stages.

### **2.8.1 INTERVIEW GUIDE**

The first stage was devising an interview schedule. A semi structured interview format was thus created. Questions covered the history of the participants' kidney problems, the participants' illness/treatment experiences (these were thought to be both relevant to a person's views on adjustment and also provide an important context for the interviewer) and participants' views on adjustment (See appendix 1).

Consistent with the qualitative method, interview schedules were not rigidly adhered to. Questions were only used as a guide, thus interesting points raised by the interviewee could be followed up in more detail. Questions were not asked in any fixed orders as they may have been covered earlier and it allowed the interview to flow more naturally.

The cyclical nature of the Grounded Theory method meant that themes emerging in initial interviews could be followed up in subsequent interviews. The Acceptance of Illness scale (AIS) was also administered after the interviews were conducted so not to influence a participant's views. The AIS is an eight item scale (see appendix 2) on which respondents rate, on a five point scale ranging from 1 (strongly agree) to 5 (strongly disagree), the extent to which they agree or disagree with statements about their health/illness. Statements include 'I have a hard time adjusting to my illness' and 'My illness makes me feel useless at times'. However in this study participants were also asked to talk through why they had chosen particular responses and to evaluate the scale in terms of its coverage of adjustment related issues. The Illness Intrusiveness Ratings Scale (IIRS) (appendix 2) was also administered. This scale obtains ratings (from 1-7) of how much the illness and or its treatment interfere with each of thirteen domains of life. The domains include health, diet and work. The scores are summed to yield a total score.

Relatives/partners were asked a very short version of the semi structured interview questions and asked to fill in the AIS and IIRS, both in regard to their partner/relative on CAPD.

Nurses were asked to respond to questions relating to adjustment in general and in relation to the participants on CAPD.

### **2.8.2 INTERVIEW PROCEDURE**

The interviewer reiterated the purpose of the study and the confidentiality of the material.

The participants' right to stop the interview or not answer any question was also emphasised.

Participants were also asked again if they permitted the interview to be recorded.

As noted above patients and partners/relatives were interviewed separately. This was partly achieved by the interviewer arriving before the relative/partner got home from work.

However for others, no problems were encountered, with participants agreeing to be interviewed separately.

During the interview every effort was made to check the participants' understanding and meanings instead of relying on the interviewer's own assumptions.

### **2.8.3 DATA ANALYSIS METHODS**

The analysis process followed grounded Theory guidelines as set out by Strauss and Corbin (1990), but it also drew on the writings of other researchers who have used and adapted these methods e.g. Charmaz (1990).

The analysis will be described as a sequence of stages but in reality these stages are artificial as the researcher is constantly moving between different levels of analysis, sometimes performing them simultaneously, sometimes moving back and forth between them.

All transcripts were transcribed verbatim and comments also noted such as heightened tone and pauses. Scripts were read many times to familiarise the interviewer with the transcripts. Specific techniques were then applied to the data. These will now be considered.

#### **2.8.4 OPEN CODING**

Open coding is the first basic analytic step and involved naming and categorising phenomena through close examination of the data. During this process the data was broken down into its constituent parts by noting and labelling emerging concepts. Initially every line of transcript was coded as this helped the researcher remain close to the data and dispel earlier pre-conceived assumptions about the data. An example of the researcher's open coding is presented in appendix 3.

In order to aid the process of open coding and help open up the data, various strategies were used. Firstly the researcher asked questions of the data such as what is this? what does it represent? The second method, called the constant-comparative method is central to the grounded theory approach. It involved comparing emerging concepts to those already identified, within cases and between thus ensuring that the full diversity and complexity of the data was explored (Henwood and Pidgeon 1992). If the emerging concepts were similar they were clustered together, if they were different they formed new concepts. More abstract categories were then developed from clustered concepts. The properties and dimensions of the categories were also developed in parallel to this.

A number of techniques were used that were designed to enhance the theoretical sensitivity of the analysis and to help prevent the researcher's own assumptions and biases gained from experience and reading, colour the data. These included asking questions about the data such as, who? when? what? where? How much?; use of the flip flop technique where the researcher turned a concept upside down to imagine the opposite, and use of systematic comparisons. These are described in more detail by Strauss and Corbin (1990).

At this stage, interrelationship between the categories were already beginning to be noted and this leads on to the next stage called Axial coding.

### **2.8.5 AXIAL CODING**

When the data had been sorted into categories the analysis turned to the process of axial coding. This process involved making connections between the categories, their properties and dimensions, the aim being to identify several main categories in which others could be grouped.

Each category was developed in terms of the paradigm model. This is where the focus was on specifying a category (phenomenon) in terms of its *Causal Conditions* (the conditions that give rise to it); the *Context* (its specific set of properties) in which it is embedded; the *Intervening Conditions* (the structural conditions that influence the categories); the *Interaction Action Strategies* (strategies devised to manage, handle, carry or respond to the phenomenon); and finally the *Consequences* (outcome on the interaction strategies). These specifying features of a category are named the subcategories because they relate to the main category (Strauss and Corbin 1990).

Such a process was a complicated and time consuming endeavour. Both processes involved the researcher constantly moving between deductive and inductive thinking as proposed relationship between categories were compared with the transcripts.

### **2.8.6 SELECTIVE CODING**

Selective coding is the last process and involved identifying the core category. The core category is the central phenomenon under which all the other categories are subsumed.

This subsumation is not that different to axial coding and uses the paradigm model.

However, it is done at a higher abstract level of analysis.

### **2.8.7 MEMOS**

Throughout the whole analysis the researcher wrote memos. These contained the thoughts and ideas relating to the data and the emerging categories and theory. They helped to order the vast amount of data collected and in assisting movement away from the data to more abstract levels of thinking.

## **2.9 RESEARCHERS ASSUMPTIONS**

As mentioned above, qualitative research acknowledges the role of the researcher in the analysis process and furthermore this must be stated openly.

In this case a literature review was conducted, and an interview guide produced and these formed part of the researcher's assumptions and guiding thoughts.

However, to help ensure the researcher kept on the analytic path, as analysis of the research began and concepts were emerging these were developed and modified by peers in a weekly qualitative research support seminar.

## RESULTS

### 3.0 ACCOUNT OF THE ANALYSIS

The first part of this section will describe the categories and their corresponding sub categories, developed using the Grounded Theory approach outlined previously (section 2.5). Five main categories were identified in this study that will be described in turn: Getting back to life, Making adaptations, Coping skills, Experiencing losses and Taking on board a new approach to being and living.

These categories will be presented as a dynamic process in which categories not only result in, or lead on to other categories, but also feed back into other categories in certain situations. However it was apparent that the category 'Taking on board a new approach to being and living', was related to all the other four categories and so is shown to encompass these categories in figure 1.

Although the emphasis of the analysis will centre on the conceptualisations of the participants on CAPD, the conceptualisations of nursing staff and relatives/partners will also be considered in the analysis, with contrasts and concordances noted.

**Key:** -All the names of categories, subcategories, properties and dimensions will be in bold print. Quotes from participants that illustrate the text will be in italics. Where S is used at the front of a quote this denotes the participant's dialogue, when I is used this denotes the interviewer's comments and questions. Where words were emphasised by participants, capital letters will be used and pauses will be indicated by: .....

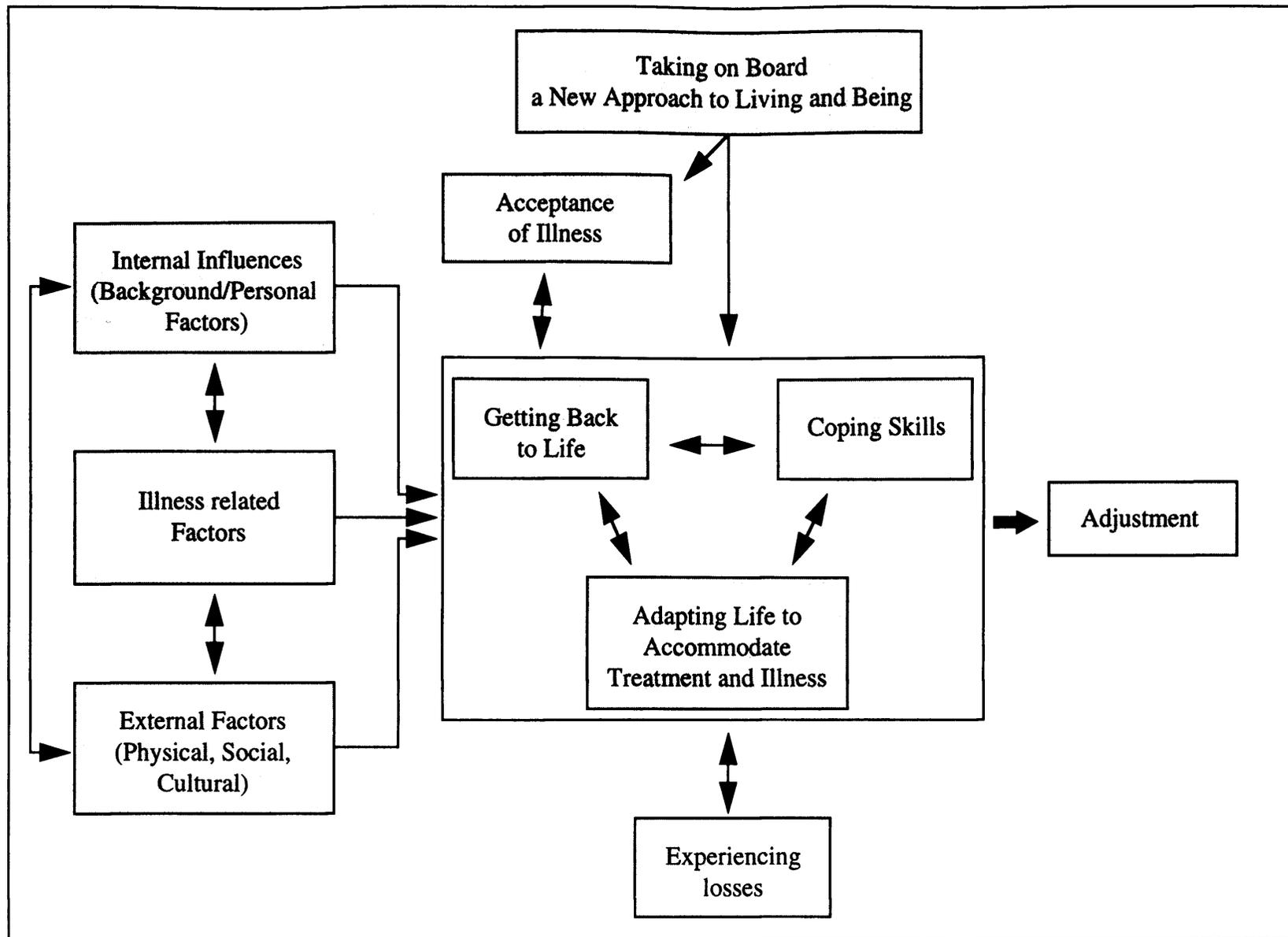


Figure 1. A Theoretical Framework for Conceptualising Adjustment to Illness.

The second part of this analysis will comment on the results of the Acceptance/Adjustment to illness scale (AIS), namely if subjective reporting of adjustment corresponded to AIS scores. IIRS scores and comments given will also be considered.

### **3.1 CONTEXT**

As mentioned in the introduction, before patients begin dialysis they usually have experienced a period of illness which can vary in length, depending on the cause of the kidney failure. During such time patients can feel increasingly tired, until making a cup of tea is overwhelmingly exhausting. They may have extremely bad headaches and be sick-daily. So by the time some patients have reached ESRF their quality of life can be very poor. However this is not the case for all patients and some can reach ESRF and experience very few physical symptoms. Once dialysis begins patients can slowly expect to feel better but other complications may mean this is not always the case.

### **3.2 GETTING BACK TO LIFE**

*“...even at the training stage I was saying I just wanted to get back to life” (10:26).*

All participants interviewed, felt that they had adjusted to their illness. They expressed the belief that an important indication of ‘adjustment to illness’, was the act of returning to a satisfactory life. This involved the participants accepting the limitations that the illness and treatment imposed on their lives and making the most of what they had left.

*S-You just get on with it, now...that’s it really. If you have adjusted you try and get back to what’s normal as far as you can (4:17).*

*S-YOU TRY ....TO MAKE THE MOST OF WHAT YOU HAVE, you know,  
just get on with where you left off sort of thing...(6:17)*

Nursing staff concurred with this thought.

*S- Dialysis is a small part in a big jigsaw, if you like and adjustment has to be  
about their whole lifestyle, not just about doing exchanges but resuming their life  
style (13:2).*

Participants illness experiences differed in terms of the **degree, duration** and **extent** of physical symptoms and these obviously set perimeters around how far they were able to **get back to life**. For example some participants felt very well after beginning their treatment and they strived for the same lifestyle they had before they reached ESRF.

*S-I just try and live a normal life.....I try and live as before and not make it a  
handicap (9:4).*

*S-Now I feel much better I'm just going to try getting on with things ..like before,  
you know. (8:14).*

Whereas other participants had health difficulties, such as breathlessness, that affected their mobility and thus, **getting back to life** could mean relinquishing large parts of their old life style.

*S-Somethings have to change that's the way it is -got to accept it, you see (3:8).*

Participant 4 had had to change her lifestyle dramatically from giving up her job to curtailing house work -

*S-Oh yes it is a lot more restricted now. It took a while to come to terms with  
this.....I decided that this is the way life is going to be. So you have to accept it  
(4:14).*

The above quote also illustrates the emotional aspects of **Getting back to life**, specifically coming to terms with the consequences of the illness.

**Getting back to life** also had properties such as **speed**, (ranging from **rapid** to **prolonged**), **degree**, (ranging from **partial** to **complete**) and **course**. The **course** could be conceptualised as a sequence of stages. Firstly, participants had to recognise their limitations, secondly, make attempts to **get back to life** and thirdly **make adaptations** when necessary (this is a category in itself and will be discussed later in this section).

Participants varied in the course that they took. These variations can be represented on a continuum. Although the sample interviewed did not represent the extreme ends of this continuum these were identified in the nursing staff interviews. At one end there were those that retreated into their illness, withdrawing from social, personal and vocational life. Thus they failed to **get back to life**. This was considered by both the nurses and some patients interviewed as indicative of maladjustment.

*(I-If you were not adjusted how would things be different?)*

*S -You would probably still do your treatment ....but you would find it hard to go out and socialise, you would probably become quite isolated sitting and being depressed (7:17).*

At the other extreme of this continuum were those subjects that wanted to go beyond **getting back to life** and undertake feats that they may not have considered doing before their illness.

*S- One chap went skiing you know you always get people who want to do things that they never did before, to in a way to sort of defy their illness I suppose (11:11).*

One can hypothesise that this continuum would have behavioural, cognitive and emotional elements to it. Participant 7, quoted above, highlighted the emotional and behavioural aspects of retreating into illness, depression and inactivity respectively. In addition to this, these three elements do not always work in synchrony. For example the nurses highlighted patients whose behaviour indicated that they were **getting back to life** but in reality they were finding it hard at an emotional level to accept their illness. They may appear to be transcending acceptance but were moving into a denial of their illness.

*S- I think there are an AWFUL LOT OF PEOPLE who have gone back to work, but who have not adjusted at all.....Really they are CRUMBLING and can end up in an acute state. This can happen because they do not want to admit they have the illness. They carry on despite feeling ill. Then they crash and end up in hospital (12:10).*

*S- Then there are those people who ALMOST do not have TIME for their own illness. You know they are often perceived to be adjusted because they work and carry on as normal but they are actually working to maintain their feelings of self worth and yes they do their bags but reluctantly (12:12).*

Another important theme highlighted by the nurses interviewed was that emotional adjustment was something that was neglected by medical staff. If a patient was **getting back to life** in his/her behaviour then that was considered to be adjustment. For example:

*S-I think medical staff are very guilty of thinking that if a person has gone back to work then they have adjusted (12:10).*

It was also stated that:

*S-Staff feel uncomfortable about dealing with this (patients feelings) and, staff need to be skilled in identifying emotional problems in adjustment (13:5).*

**Getting back to life** was achieved via a number of action strategies that were both purposeful and reflexive in nature. These were **health gains**, **re-establishing roles** and **copng skills**. The first two will now be described but the last is discussed as a separate category.

### 3.2.1 PHYSICAL HEALTH GAINS

Firstly it was apparent that participants needed to experience some **physical health gains** before anything else and this was achieved by following the self care regime.

For some participants the predialysis period and beyond was characterised by increasingly severe uraemic symptoms, the most debilitating appeared to be the tiredness that was encountered.

*S-Well you cannot imagine being so tired for so long,*

*You just feel too tired to breathe it is just you cannot be bothered to live but at a practical level you know you want to get on with life but you just cannot be bothered (10:13).*

Participants varied in the **degree** and **speed** in which they felt well again. Amongst those who had been on CAPD for six weeks, four were feeling much better while two still were grappling with some physical problems such as tiredness and breathing difficulties. For those at twelve months only one was experiencing significant health difficulties. This could be considered as the first step to **getting back to life** as this was indicated by both participants at six weeks and twelve months and the nursing staff.

### 3.2.2 RE-ESTABLISHING ROLES/VALUED ACTIVITIES

Once participants had begun to feel better they then set about resuming life. This was achieved by re-establishing important roles, where possible. For some of the participants one of the most important roles was **work**. If they could continue to work they would be able to retain both their feeling of self worth and their pre-illness quality of life (as financial difficulties would not be a concern).

*S-It was very important for me to get back to a life, get back to working, then in that way I still have a normal existence and feel better about myself (2:15).*

*S-I just wanted to get back to work, earn some money again.....That was very important. I think that is a good thing to do to... adjust you see.....(5:11).*

However, for some this was not a priority, participant 8 for example “gladly and willingly” decided to give up her manual work but ensured that her valued **social** and **family roles** were maintained and participant 4 re-established her **family role**:

*S-but I still make sure I do all those things I USED TO LIKE going out with friends and well, I suppose being a house wife (8:20).*

*S- I'm a grandma and I can still spoil my kids! (4:20).*

There was a sense that participants wanted to maintain some semblance of normality as they strived to **re-establish roles and activities**. **Re establishing roles/activities** could sometimes be blocked by others or by the treatment and illness, such as participant 9 who had his work duties reduced by his employer. He commented that they thought ‘he was always sick’, whereas he felt perfectly able to continue with the same work and the same hours. He was left feeling powerless, stigmatised and angry:-

*S-They think you are always sick.....sick all the time, but I am not. IT'S SO FRUSTRATING. Work is very important part of life and now I DO LESS DUTIES and part time but what do you do?....cannot rock the boat...may not want me back (9:8).*

Participant 1 was made redundant and hinted at the stigma of his illness:

*S-The redundancy was unfair,, the recession hit hard... PLUS THE FACT that I had just started dialysis so I was off for nearly a year.*

*I- How did you feel about that?*

*It was hard because you felt it was because of the dialysis ...I still felt OK but they did not see it like that.(1:6)*

Illness can obviously block the **re-establishment of roles/activities**. However, where other valued activities are able to be maintained, life may not seem so restricted. For example participant 6 relinquished playing football and watching matches but still drove his car. It could be hypothesised that his highly valued independence, was maintained.

*S-Oh yes I used to play footy-and go to matches but I cannot do it now because I cannot stand for long. I used to go and watch city play but it's now impossible.*

*Oh of course I can get around in my car, so I am HAPPY WITH that .....As long as I can go and see relatives I can do that and go to the shops, just get around (6:25).*

Nursing staff also emphasised the importance of **re-establishing roles or activities** and that these would vary depending on the circumstances of the person.

*I- When someone says they have adjusted to their illness, what would that mean to you?*

*S- I would say going to back to work, an acceptable quality of life that may not be doing the same thing that they were doing before dialysis, going back to work, for them, may not be important, but going back to do certain social things or just feeling better may see that as adjustment (12:3).*

It was apparent that as participants attempted to re-establish roles in some areas, adaptations were necessary as suggested in the above quote. Implementing these adaptations was another indication of adjustment to illness. This forms the second category developed using the Grounded Theory approach.

### **3.3 MAKING ADAPTATIONS TO LIFE TO ACCOMMODATE ILLNESS AND TREATMENT**

This process involved participants acknowledging that some changes had to be made to the way that they did things and the way that they thought about things. It also involved participants attempting to adapt parts of their social and personal lives.

The following sub categories ‘**incorporating treatment into the routine of life**’ and ‘**modifying goals and activities**’ were identified as actions taken to achieve adaptation.

They will now be discussed below.

#### **3.3.1 INCORPORATING TREATMENT INTO THE ROUTINE OF LIFE**

Participants expressed the belief that an important part of adapting to their illness was incorporating self care behaviours into the routine of their lives.

*S-You see you not only have to adjust emotionally but you have to adjust to the new routine of dialysis. It takes a while to fit it in, get a routine going like collection of the bags on Tuesday morning (10:9).*

*S-Now it's part of everyday life. It becomes part of you routine (5:12).*

*S-Well I said to myself come on get on with it..... Gradually you get to do it automatically -like driving a car and it's just part of what you do (6:20).*

Resolution of this incorporation process seemed to begin with the treatment being performed proficiently and automatically as highlighted by participant 6 quoted above.

This process was not without difficulties. Each participant found that there were some aspects of the treatment, usually the injections, that were unpleasant to them, whilst others found the diet and fluid restrictions difficult to adjust to.

*S-I had a problem accepting that I had to do the epo injections. I used to think I do not want to do it. It used to take me ages to get myself to do it. But now it's fine and the treatment does not bother me at all.(2:16).*

*S-Then there is the injection that I CANNOT DO AT ALL. I cannot put a needle in my hand I pass out on the floor (3:4).*

Within this sub category there were some variations with how participants **incorporated their treatment** into their routine. Again this variation could be considered to lie on a continuum. At one end were those that seemed to emphasise the importance of **integrating** the treatment into their lifestyle. These subjects attempted to minimise the disruption to their lives by not allowing treatment to **interfere** extensively with daily living.

Participant 1 stated:

*S-Now I tend to do them anywhere. I can do it at work, in the shopping centre. It is a process of getting used to it. You know I used to sit down to do exchanges but now I can walk around and do it.(1:9)*

This participant's partner concurred with this. When asked if her husband had adjusted :

*S-.....It has not stopped us doing things. He has no worries about doing his exchanges out and about. He has done it in the car and like sometimes we have rung and found out if there is a place we can do exchanges before visiting some places and they have always been accommodating (1a:2).*

Participant 8 noted:

*S-The other week I went into Leicester with some friends and sat in the car and did it! I have even done it in the pub car park. I mean the first time was a bit scary I thought I'll never cope with this but I have heard others do it and so I thought I'll have a go, you have to really, otherwise you will never go out! (8:10).*

Participant 10 emphasised that not only is it important to organise dialysis around your lifestyle but that whilst dialysing a wide range of activities can be undertaken. She felt this should be emphasised by nursing staff.

*S-I decided that if I was not going to resent being on CAPD that I was going to have to fit it into an activity so that's what I did. So I would put my bag on and then come down and eat breakfast for the first one. Then lunchtime I am at work I put my bag on and carry on working, I answer the phone, write reports sit in an office with ten people and get on with my job (10:10).*

At the other end of the continuum are those who allowed their treatment to intrude into their routine. For example some participants emphasised that treatment was such a priority, that their day, to a certain extent, fitted around their treatment. In spite of this they viewed this as a positive attempt to adjust to their condition.

Participant 3 stated:-

*S-Well I accept that I cannot go out as I used to. If I go into town I have to come back before lunch to do my exchanges and I cannot go out for the day because I*

*need to get back... I will be watching the clock..... You know adjustment can be about trying to make it part of your day but fitting around it (3:6).*

Participant 7 noted:-

*S-Well I cannot go out for day trips anymore. We used to clear off for the day but now.....I have to think my bags need changing at so and so a time and we would need to take these things with us so we are not as free as we used to be.....(7:5).*

Participants gave different reasons for allowing this intrusion into their lives. For example one participant wanted their exchange to be done hygienically and thought this would best be achieved at home. Another could not bear the thought of doing it in public, fearing that every one would stare at her. Each one also felt that in the future they may attempt to take their bags out and go for the day. It was felt that for some participants, their motivation for doing this appeared to be related to their concern about how their partners or relatives lives were being be restricted.

*S-I know it hits my wife hard she has to stay in as well. I am going to try and get out in the summer, take her out for the day (7:20).*

*S-My daughters gets frustrated .....you know having to bring me back at lunch time. I would like to be able, perhaps one day, to take a bag (3:9).*

Participants who emphasised that treatment was a priority over their daily life had, in most cases, more severe physical symptoms associated with their illness and tended to be the older participants. However, it was also evident that these participants were also those who were more resigned compared to other participants, to relinquish activities associated with their past healthy life.

*S-Well it does not bother me as much now.... It is more restricted now but I have decided that this is the way that life is going to be so you have to accept it (7:5).*

When this participant was asked how he felt about not being able to go on holiday, he replied:-

*S-Well it is something you have to accept really, you cannot moan and groan about it because there is nothing you can do... but it,....If you accept, it makes it easier (7:6).*

Interestingly most of the ‘integrators’ thought “clock watching” (regarding exchanges) and ‘letting treatment rule your routine’ was an indication that someone had not adjusted to their illness.

*S-If you were not adjusted you would let it take over your life....Everything would stop for treatment. You would clock watch like I used to do. let it stop you doing things (8:24).*

*S- I suppose that would show that someone was not adjusting if they let it run their life you just get on with it work around the dialysis do what you do normally (1:12).*

Partners and relatives concurred that their relative/partner on CAPD had adjusted to their illness regardless of whether they tried to integrate treatment into their life or live life around their treatment. However there was frustration at some of the restrictions imposed and in some cases it was felt that the their partner/relative was leading an unnecessarily restricted life.

*S- Sometimes she could probably do more like she does not even go and sit in the garden like she did because she does not want to fall asleep and miss an exchange (3a:5).*

*S- He gets tired more easily and so cannot like mow the lawn all day....He is tired after a couple of hours. Sometimes I think it is all in the mind! It is a good excuse, anyway he could probably do more than he does but then maybe he has always been like that (5a:2).*

### **3.3.2 MODIFYING GOALS AND ACTIVITIES**

Another important way to achieve adaptation was by **modifying goals and activities**.

This involved participants recognising that this was necessary and then implementing the appropriate changes. For the CAPD patients these ranged from the modification of their diet and leisure pursuits to the modification of personal goals and aspirations.

While some participants felt that modifying their diet and fluid intake was not too much of a problem, those who regularly would go to bars and pubs in order to socialise found this to have wider implications.

*S-You see I cannot drink as much as I used to like go down the pub for a couple of pints or more but now I may have a spirit every now and then. You just change things like you can still go down but it is difficult sometimes (6:17).*

Leisure activities and holidays were also no longer straight forward, for example holidays involved much more planning to ensure that bags were either taken or delivered and there were also restrictions on where it was possible to go.

*S-You realise that you cannot go on holidays like trekking in the wilds for days you know you accept that this is the case but you then choose to do something else you know like we can go off to Europe if we plan ahead (1:4).*

*S-I cannot go swimming anymore -(laughs) and we had just joined a leisure centre to do that.....but I play golf , keep active that way (5:17).*

For some participants **making adaptations** meant modifying personal aspirations and goals.

*S-I used to want to go travelling -you know in retirement but this has put the downers on that really but you can still go away to other places where they send your bags (6: 17).*

Participant 5 made some changes that he felt were for the better:

*S- I mean I was at the stage where if I had not been on dialysis I would have sat back a bit to take things a bit easier but I thought I cannot do that. This is me, rather than work (not influenced by people at work). I suppose life takes on a new perspective and I was ready to retire but now because of the kidney failure I do not want to, I want to prove I can still do it.*

*I- How did you feel about that change?*

*S- It's a positive one really (5:7).*

Some participants with partners were able to talk about how it was important to find ways of maintaining intimacy despite the catheter. While some managed to adapt to this others abstained from any aspect of intimacy. This will be discussed further in the **Experiencing losses** section.

Modifying goals and activities seemed also applicable for those participants who talked about life before starting dialysis. As the illness took hold participants had to make modifications. Participant 10 highlights the cognitive modifications she made when she realised that she was not going to be able to perform her job to the best of her ability.

*S-That was something I had to come to terms with. I had to say to myself look you can still do the basics do what a lot of other people do anyway when they are*

*well, you just have to wait until you get better before you can put your heart and soul into it (10: 24).*

Nursing staff highlighted that adaptation incorporated patients realising that some things needed to change such as work by maybe finding a different type of work or finding some other activities to enjoy. Such recognition on the patients part was seen as a good adjustment but it was also emphasised that at an emotional level patients could find it difficult to accept.

*S-Some people have to give up their job and we often see that as a negative thing although it can be a sign of a positive adjustment because they have realised that the limitations on dialysis means they cannot continue with their job, especially if it is hard labour and if they can take on another role e.g. voluntary work, which means they still perceive themselves as a worthwhile person .....(12:2).*

The two categories, **getting back to life** and **making adaptations** discussed above, were complicated by certain factors. For example the **speed, extent** and **degree** to which **both** processes could be realised, depended, to a large extent, upon a number of intervening conditions, either **external** or **internal**. **External** conditions included; the extent of physical problems; the support available from a number of different levels such as from the family, the hospital and community; material resources, such as the financial resources of the individual and the organisational level. Another important **external** influence hypothesised to be important were cultural ideas. For example in the western world a man's sense of self worth is expected to be connected to work outside the home and even women are expected to achieve self worth by working outside the home in addition to remaining the main care agents.

Participant 11 noted:

*S-I think having a job is a big factor in adjustment and acceptance. If they have a job and the employer is flexible they get a better quality of life and they have a function, their role has not changed like if they are the breadwinner they still have their own money. They can then still go out and have a better social life (11:13).*

If the ability to work was threatened in some way it could then lead onto feelings of inadequacy. Cultural beliefs in our society also extol the virtues of continuing social engagements, showing fortitude and **getting on with life**. Such values are also likely to play a part in patients' adjustment.

**Internal** conditions refer to those within the individual and included motivation and the extent of a person's coping skills. These will now be discussed as a separate category below.

### 3.4 COPING SKILLS

**Coping skills**, the third main category identified by the Grounded Theory, was defined as thoughts, behaviours and feelings that aid the person in **getting back to life, adapting** and thus adjusting to their illness.

Some participants **positively reframed their illness**, that is they re-constructed their illness and its implications in a positive way. This was achieved by the use of a number of psychological strategies. For example in cognitive optimising, participants compared themselves favourably with others. The implication being that they had been spared something far worse.

*S-Well I could be worse off, I keep reminding myself, I could have other illnesses on top of this (9:22).*

*S....No but I think if you had to give up work that would be a real problem it would be difficult to accept, like I did not have to give up work If I had it would have been very difficult (6:32).*

Another method used by participants was to identify other persons with health problems who were living particularly effective or indeed worthwhile lives with their condition. For example, participant 3 talked admiringly about a person whom she read about in the papers who had performed his exchanges on the beach. Another participant talked about someone who had been on dialysis for twenty five years. Lastly participants found that their illness actually improved their life in some way. Participant 5, for example, felt that he had re-evaluated his life and as a consequence of this he now appreciated life much more, valuing his time and feeling more relaxed than before his illness. Participant 4 was so impressed with the support of her family that she thought her illness had brought them much closer together.

*S-Well I appreciate life more that's for sure it concentrates the mind when you are told this you have to rethink what you are going to do. A classic example.....getting worked up about driving now I think I do not care less, I am more relaxed now.....more laid back than before (5:16).*

*I- Have you gained anything from your illness?*

*S- It made me realise what my family mean to me and think of me. I will say that they have been very supportive, all of them. I mean if I am going to go anywhere, my daughter will bring the kiddies and take me without argument. We are really close now (4:8).*

*I feel in a funny way that I have gained because I have got this strength, confidence and determination (10:16).*

Other coping strategies were used that **reduced the threat of the illness**. For example several participants redefined their illness as simply a problem.

*S-I do not think about it as an illness but as problem (9:5).*

*S-Well I do not think of myself as ill, infact I prefer not to think about myself as ill. I mean I do not look it or feel it for that matter (5:15).*

As illustrated in the quote above these participants tended to experience few physical problems.

**Humour** was found to be another strategy for coping with illness. One participant had problems accepting her exit site, she remarked:

*S-You have to accept this hole in your body ..... It keeps you alive.....I just laugh it off now we make jokes about it especially my husband.*

*I- Do you mind that?*

*S-No I prefer to laugh about it, keeps me sane- It's my way of coping (8:16).*

*S-All my friends have accepted it. I always show them my tube -I SHOW IT OFF! Then they know what I am talking about.(laughs). We all have a laugh about it you have to laugh THAT REALLY HELPS! (7:30).*

The quotes above also highlight that **humour** can help others cope with the exit site and illness.

**Distraction** was also a psychological technique used to cope with the illness. This was illustrated earlier on in the section describing the category **getting back to life**, where minimising illness and treatment related thoughts was a strategy that could be used purposefully.

*S-On one of my off days I feel useless, I just try and take it off my mind -then you can pull yourself together.*

*I How do you do that?*

*S- I get out a book, watch tele -that kind of thing (4:7).*

Another sub category of **coping skills** identified was **maintaining hope**. This was usually expressed as optimism for the future and all participants showed this in varying ways. For some it was for their health, some for the pursuit of future activities, some for transplants.

*S- It's going off for the day that we miss more than anything else. But maybe in the summer we will make the effort. I am going to do my exchanges outside (7:30).*

*S- I told myself I could not give up, there were brighter days ahead, I BELIEVED THAT, I think that made it easier for me (10:6).*

This type of optimism for future health gains was obviously more a feature of participants who had at present, what could be described as inconsistent and uneven days. Their level of health would fluctuate and so their optimism was directed at a time when they would feel well for the majority of the day.

*S-Well you know am I going to get a transplant. It keeps me going but I may be waiting for ages (6:23).*

For those who were feeling well, hope tended to centre on other achievements such as leisure pursuits or holidays.

Nursing staff pointed out that in some cases seemingly useful coping strategies employed by some participants could be masking difficulties. Participant 12 for example remarked:

*S-They may have a bravado front in the way they talk to people but they use humour to cope but inside I think they can be very sad and be breaking down (12:5).*

This was perceived to be especially so of some women who had not as yet come to terms with their new body image and their lost figure.

Within the category ‘**coping skills**’, there are many properties. Coping strategies used differed in the **type**, the **frequency** and the **extent** to which they were used.

Amongst some participants there seemed to be an **expectation of how one should cope**.

This could range from giving in to the illness and its effects or fighting it. In some there was a feeling that they should be grateful for life, not moan and groan but accept what they had now. This seemed to be consistent with what nursing staff reported. For example participant 12 acknowledged that they encouraged patients to:

*S-Focus on good things coming out of dialysis- the health gains.(12:5)*

and later on when talking the participants was about getting back to normal life style it was noted that:

*S-this is the mentality you try and encourage but some take it to the extreme.(12:12).*

There was a general theme that emerged from where **getting back to life** and **coping well** were strongly encouraged and positively reinforced. This is a very important issue and probably relates to even wider influences on all of us which are discussed in more detail in the category **acceptance of illness**.

### 3.5 EXPERIENCING LOSS

While participants talked about how they had adjusted to their illness and treatment, **getting back to life** and **adapting to** their new situation, at some points during the interview they were also processing some aspects of their loss experiences. For example, they were thinking and talking about how things were, focusing on the personal meaning of what had happened and remembering past roles and old routines that had gone, maybe, forever. Concomitant to this there were feelings of sadness and sorrow. Participants

talked about their lost **body part** and /or **function** with the catheter serving as a reminder of this. Some participants seemed to experience a loss of wholeness.

*S-You do feel that you are not the same person anymore...you have this pipe in your stomach you are not a full person anymore (9:10).*

*S-You feel like half a person really it's silly I know, you know, cannot explain it really but that's how you feel.*

*I- How does that make you feel?*

*S- It 's , well.....you try not to feel sad (8:17).*

Although this feeling and type of loss seemed more pertinent to those who had been on CAPD for six weeks, one participant who had been on CAPD for twelve months also experienced this sense of loss.

*S- Well the kidney is gone and I am restricted, I cannot do things like I used to. I have a kidney gone. That's part of me gone. That's hard to think about-so you don't. You just get on with it (3:14)*

(Interestingly, as illustrated in the above two quotes some participants talked about their experiences in terms of 'you' rather than the first person almost as if they were distancing themselves from their experiences.)

The nursing staff also reported on this type of loss:

*S- A lot of patients, especially those that cannot pass urine, you notice a sense of bereavement in them more than anybody else. (13:10).*

When asked how this bereavement manifested itself it was reported that :

*S- Sometimes they are angry or a bit low. Often in appearing not to be compliant not taking advice.(13:12).*

This would seem to indicate that loss can manifest itself in various forms.

The physical changes to the body, such as the scarring and change in shape as a consequence of the catheter and fluid that needed to be retained, resulted in a changed self image. Participant 8 remembered with sadness her body before “its invasion”:

*S-I used to have quite a good figure before this. That sometimes gets me upset you know.....I feel like Michelin woman as I now get so big around here, so you have to wear more baggy things like this. (8:16).*

She now found it difficult to look at her body appearing to feel a sense of shame.

*I-What have you lost as a result of your illness?*

*S-I have lost my dignity.....I cannot show my husband the exit site, he has only seen it once. It is very personal to me, even I cannot look at it at times,...couldn't before....He would not want to look at it anyway.(8:27).*

She also added:

*S-.....he does not like blood and gore. (8:27).*

However this sense of shame was not always evident in women.

*S-The first thing I did when I got home was get undressed and look in the mirror and I prepared myself, took a deep breath said to myself just pick yourself up and start again but I looked and I still was not bothered. Then I thought, am I dealing with this, (laughs) should I be upset (10:26).*

Some participants were able to talk about the changes to their psychosexual image. They had as a consequence of their change in self image or their partner's difficulty in accepting this change, refrained from sexual activity.

*S-That's a joke take it or leave it these days. Well we stopped all that now could not do it with this here. He cannot even look at it and I -it would not feel OK (8:32).*

*S-Well I suppose it has changed our relationship. But all things come to an end.*

*You know with holding hands I do not do that either any more (7:32).*

Thus with the participants quoted above had not only refrained from sexual relations but also from showing affection and other behaviours associated with a loving relationship. Participants felt they were different people now. There was a gap between how they knew themselves before CAPD and how they are now.

*I Have you had a hard time adjusting to the limitations of your illness?*

*S -Yes I did to start off with. It was having that pipe in me. You know I am a different person now I have this thing in me. I have to do things a bit different.*

*Now it is not so much of a problem but it took a while (8:29).*

Along with the physical changes that made the participants feel different there were also the lost roles and routines and the tasks which simply could not be done anymore. This was especially pertinent to those who had more serious physical problems associated with their illness.

*S- Sometimes I get fed up with my life I wish I could do what I used to do.....Get up go and get dressed then clean my house before having breakfast. Watch the tele. If I could just manage to do the things I used to do a bit more (3:12).*

For many participants at both six weeks and twelve months after reaching ESRF the loss of freedom was felt very strongly. From those who were feeling well to those who were not so well.

Participant 2, referring to his bag changes said:

*(I-Have you lost anything as a result of your illness?)*

*S-Well the freedom of doing what you like, when you like. I mean I HAVE MADE LIGHT OF IT BUT YOU HAVE TO DO THIS FOUR TIMES A DAY and one of the worse thing is at night (2:6).*

Anticipated future losses were also evident especially so for those who had been on CAPD for twelve months. It appeared that reaching a resolution of these losses was probably not achieved. This was demonstrated by those participants at twelve months who were still talking about things that they missed in addition to focusing on future losses. It could be hypothesised that loss is an ongoing feature of ESRF. Several contributing factors could be fluctuating health, an uncertain future and constant reminders of their losses.

However for the majority of the time it appeared that patients included in this study were getting on with life, feeling satisfied and neutral.

There was however, a variation in the **extent, intensity and duration** to which participants experienced or acknowledged these losses. It could be hypothesised that intervening **internal** and **external** factors that were mentioned previously, were also important. Some participants also seemed to experience more intense feelings of loss upon diagnosis and immediately after. These feelings had thus been worked through over a period of time so that once ESRF had been reached, loss was not a significant feature.

It was also clear from the interviews that some participants who held emotions such as anger and those associated with loss, considered it not to be useful to express these feelings even when felt. This was not only for the benefit of the participant but also for others such as the family, medical staff and employers. For some participants underlying this there was a sense of powerlessness, in that they believed that if such emotions were expressed it could result in rejection.

*S-I wish I could do what I used .....It makes me feel sick I feel so angry..*

*Sometimes I just cannot do it. Family have to but I cannot be ungrateful (3:13).*

Later on she said:

*S-Oh yes I feel useless but I do not get angry, I come to terms and be satisfied but I do get frustrated because I cannot do nothing you know I look at my kitchen and I cannot do like I used to. These things work me up and I have to come back down and not let them get to me. I rely on others too much (3:19).*

Interestingly issues pertaining to a reduced life expectancy were rarely mentioned. Maybe such issues had already been worked through upon diagnosis or such thoughts were suppressed. There was one exception, for example participant 10 described how she had confronted this issue soon after she had received her diagnosis and had now accepted it.

*S-I went on a bus once and I got a very dear friend and we have often laughed about being two old biddies when we are old gossiping talking about men and I went on this bus and was not long diagnosed and two old ladies were sat in front of me and they got their face powder on and the lipstick and I felt really sad because I thought I am never going to get to that stage sitting with my friend.  
(10:19)*

Later on she said

*S-I think that has been where my strength has come from because I have come to terms with dying (10:20).*

### **3.6 TAKING ON BOARD A NEW APPROACH TO BEING AND LIVING**

**Taking on board a new approach to being and living** was identified as a core category (see figure 1). It encompassed the processes noted in the categories **getting back to life**

and **adapting life to accommodate illness**. An important sub category mobilising this process and indeed some of the processes from the other categories just mentioned, is

**Accepting the illness.**

### **3.6.1 ACCEPTING THE ILLNESS**

Participants who accepted their illness were able to acknowledge its existence and its permanent nature.

*S-I have accepted that I have this, I know its permanent..... and that I need to do this treatment (7:10).*

*S-I have accepted it. You have gained something that you do not want, -but you accept it. If you reject it you never change the way you do things -WHICH OF COURSE YOU HAVE TO..... TO SURVIVE (3:10).*

Nursing staff concurred with this:

*S-Acceptance is about when you have looked at, defined what your illness is about. I think you move from acceptance which is about accepting that there will be limitations and that some adapting of life will need to be done (13:8).*

This category was further deconstructed to include three additional components namely, emotional acceptance, behavioural acceptance and cognitive acceptance. Each of these will be considered in turn.

### **3.6.2 EMOTIONAL ACCEPTANCE.**

Acceptance was considered to be a state of mind characterised by positive affect.

Although participants reported experiencing low mood at times, this was intermittent and normalised.

*S- I have good days and bad days.*

*I- What happens on a bad day?*

*S-Sometimes I feel low, could be ill or just down. But then on good days I feel fine, not really depressed, look out the window thank God I am alive (3:10).*

*S-You know I have felt low over the last year you are bound to really. You know I have moments when I feel useless, no good to anybody, I sit here just being a burden. That's one of my off days (4:10).*

Such feelings were also qualitatively different to the emotional state thought to characterise someone who was considered to have rejected their illness. For example these people would feel a deep sense of futility, be depressed and would want to give up. All the emotional reactions that are often associated with loss in general.

*I-What would life be like if you had not adjusted to your illness?*

*S-If you cannot accept it, it would be very hard . I would not want to be in their shoes. You would have no will to live (6:28).*

*S-But if you could not accept it you would be very depressed you would have no will to live .....It would drive you mad.....I am glad I am not like that. You would probably still do your treatment because that is not hard to do (7:17).*

Participants actually found it very difficult to envisage what life may be like for someone who was non accepting and non adjusted to their illness. Some had obviously just never contemplated such a thing, while some turned to a period when they felt they were not adjusted. Participant 10 turned to a description of how, in coming to terms with her diagnosis in the early days, had lead to cognitive difficulties and concentration problems as an example of not being adjusted.

*.S..... It effected me cognitively. Thinking through things. I could not quite get it out of my mind, although I was not really aware of it. I felt anxious and uptight thinking about it my head was just full of kidney disease (10:30).*

Participants may have had a number of years to emotionally accept and come to terms with their illness. Thus it may be that if patients who were newly diagnosed were asked questions relating to adjustment they would be experiencing more negative emotions. Again these would be ‘normal’ feelings. Participant 10 noted that it was important to work through such feelings and was ‘horrified’ when her GP recommended antidepressants.

*S- I said that I was not having anti-depressants because I recognised that it was because I was trying to deal with things. I was not able to concentrate on the things I should have been. There was no point in trying to hide it I had to let it out (10: 30).*

Emotional catharsis maybe uncomfortable for the medical professional but this quote illustrates how this participant wanted and felt it important to ‘have’ her emotions.

As highlighted in the category **Experiencing losses**, participants may have talked of their gratefulness for their treatment but underlying this were also feelings of loss which intensified as they realised the full impact that their treatment and illness would have on their lives. Loosing the function of an organ or activities that they used to be able to achieve had implications for their self identity and their self image. However, participants spent (probably) the majority of time feeling reasonably happy and thus it did not prevent them from feeling that they had **accepted their illness**. Again it could be hypothesised that if someone was feeling overwhelmed with the sense of loss they would find it hard to accept their illness.

### 3.6.3 BEHAVIOURAL ACCEPTANCE

As discussed earlier, a key behavioural feature of illness acceptance was performing the self care regime. This included the exchanges, medication, diet and fluid restrictions and injections. For some participants this seemed to be how their acceptance was manifested.

*I-I do all my exchanges and do what they tell me, so yes I have accepted it (7:13).*

**Getting back to a normal life and adapting** by setting about doing tasks differently were also behaviours that seemed to be examples of behavioural acceptance.

Non-acceptance was thought to be characterised by non activity with a concomitant lack of desire to return to a social and vocational life. Rejection of illness and treatment could also have led to the wish to commit passive suicide by cessation of the self care regime.

Nursing staff seemed to have the perception that the medical professionals take behavioural features such as returning to work and compliance with treatment, as the key measurement of acceptance. However, they highlighted that someone could be going back to work but emotionally not able to accept their illness. This was illustrated in an indirect way by participants continuing to work despite dialysis but were still trying to come to terms with their illness.

### 3.6.4 COGNITIVE ACCEPTANCE

This was characterised by the absence of worrying thoughts about illness or treatment. It was also described by participants as a state of mind characterised by positivity and hope.

*S-I have accepted it. It don't bother me like it used to. It used to worry me*

*whenever I got the bag out if it was not going a certain speed I USED TO PANIC,*

*I USED TO THINK THERE WAS SOMETHING WRONG but now I do not worry about*

*it.-It does not rest on my mind, that's the only way to cope with it (4:17).*

*S-well I think about it in terms of coming up against something that is new, turning it around in you head and finding a way of it not upsetting you (10:27).*

The properties above also interrelate with each other. For example participant 4 and 10 described the relationship between cognitions and emotional state.

*S-It means I just learn to live with it and get on. Not think about it for too long other wise you might get depressed (4:19).*

Participant 6 illustrated the relationship between cognitive, emotional and behavioural elements.

*S-Well it was very difficult at first I GOT REALLY LOW LIKE. Then I HAD TO SAY to myself you have no option you have got to do it. Gradually you get to do it automatic. It's part of what you do. You accepted it (6:20).*

As highlighted earlier these three aspects of acceptance may not necessarily occur at the same time. This is illustrated by Participant 11:

*S- There is a difference between what you hear from medical staff who think that someone is doing well, yes they may be doing well with the treatment but when you talk to them they are emotionally quite low, they talk about living on borrowed time (11:9).*

Some participants made reference to aspects of acceptance being a character trait.

*S-I tend not to get depressed about things (5:8).*

*S-Well I accept things very easily. Like when I took some tablets that made my sight go and I lost it for five days, but I accepted it and then it came back. I do not dwell on things it does not do you any good (7:11).*

*S-Well I always have a positive attitude, always have been able to accept things. I am easy going. That has helped me accept things that's very important (4:23).*

However, there was also clear evidence that **Accepting illness** could be a gradual process.

*S-I found it hard to start with -you know accepting this illness and treatment but gradually you learn to live with it and that's it really (3:14).*

This was confirmed by the relative:-

*S-I mean it took a few months for her to come out of herself....You know she was very depressed to start with but now she is better, although obviously she gets low at times for a number of reasons (3A:3).*

Intervening conditions could obviously effect the **extent**, and **degree** of acceptance. Again the **external** and **internal** intervening conditions mentioned earlier such as state of health, action of others, material resources available can mean that a person's state of mind, life situation can change and move them into rejection of their illness.

Participants highlighted several interaction strategies that aided them in accepting their illness. **Length of illness** meant that some had been prepared for their dialysis for quite some time. Participants lived with their chronic condition for a range of one to six years, although for some the onset was much quicker. They were thus aware that they would be needing treatment.

*S-There was really no big shocks for me. I had been in out patients for three years so nothing was a shock I KNEW IT WAS COMING (1:10).*

*S-Well they had told you that it would come to it. So it was not -should not be a shock to you. It should not be a shock to anybody (9:2).*

Following this he said:

*S-They told me that there is a problem but you do not realise they have an answer for it I suppose you do not take it on board you just forget it put it out of your mind until it happens (9:2).*

Another important factor was **health status**. If participants felt well then it was easier to accept their illness. Nursing staff concurred with this.

*S-The only time I have felt fed up is when I have been feeling pretty awful I had some chest infections so it was hard to accept then (1:14).*

*S-I feel better and that has helped me accept the treatment and illness.*

*S-I have accepted it 70%.*

*I- Could you tell me about the 70%?*

*S-Well I have got that far accepting it but I WANT TO GET RID OF THIS PROBLEM IN THE MORNING (feeling poorly) then I would be quite happy.....Cause you know I feel that ill when I get a sweat on ....and I sit down, I feel like I am going to pass out. Well when I sort this out I'll be fine (6:24).*

*S- Health is very important. If we can get them well on dialysis that is a major step forward. If they were really well on dialysis then that can be a useful factor because they can see improvement and then they are more accepting of it (12:14).*

### 3.6.5 INTEGRATING ILLNESS/TREATMENT INTO IDENTITY

*“This is a part of you now, who you are.” (10:28).*

The final sub category of **Taking on board a new understanding of being** is labelled **integrating illness into identity**. Participants can differ as to how far this occurs. For some it seems to partly dominate their identity, becomes part of everything that they do and defines their relationships. Whereas for others it becomes only a dimension of themselves. This seemed to distinguish what have been termed **active** acceptors, from **resigned** acceptors respectively. **Active** acceptors were participants who wanted to ensure that the illness did not interfere with their life, they emphasised **integrating** treatment into their

routine, **getting back to activities and roles** they used to do and **making adapting** where necessary. They emphasised the importance of **containing the illness**, such that the illness did not spill into all areas of their lives.

**Containing illness** also had a cognitive, behavioural and emotional dimension to it. At the behavioural level participants felt it important that their lives had **minimal disruption** and this was achieved by such behaviours as the resumption of work or continuing with valued activities and doing activities while dialysing. At the cognitive level participants felt that **having minimal intrusive /illness related thoughts** was important and an indication of adjustment.

*S-It does not prey on my mind so it does not bother me now, I am not frightened of it (1:11).*

*S- once you have accepted it you do not let it linger on your mind...do not let it get you stressed (9:21).*

As the above quotes illustrate illness related thoughts also affect emotional state by reducing anxiety. It is also evident that this could be a purposeful coping strategy or an automatic process.

Experiencing few worrying thoughts appeared to be the consequence of 1) performing treatment confidently and 2) retaining other important roles /activities in their life.

**Resigned** acceptors were characterised by being physically less well. They were also more willing to relinquish past activities, goals and roles and let treatment interfere with their routines. These participants may have more adjustments to make in their life but they are more willing to submit. One could hypothesise that the **uncertainty** of how they are going to feel on a certain day could cause major disruption to their lives and so social, leisure and

work activities are curtailed. The balance tips into submission and soon treatment is prioritised.

These two types of acceptance probably lie on a continuum with participants in this study lying at various positions on this. However regardless of their position on the continuum, all of the participants stated that they had adjusted to their illness.

### **3.7 COMMENTS ON THE ON AIS AND IIRS**

Scores for the two questionnaires are presented in figure 2. The scores marked with a \* represent those participants who were found to be resigned in their acceptance of their illness. It is noticeable that their scores are lower than other participants who were identified in the interview, as being more active in their acceptance. Furthermore it was found that subjective reportings of adjustment for some of the more resigned participants, were not consistent with their scores.

A closer look at the questionnaire revealed participants who were more resigned were in high agreement with the questions relating to being a burden, feeling useless and dependent (questions 2,3,4,5 see appendix). Although participants generally found it difficult to comment on the questions from the scale some remarked that anybody with a chronic illness would experience feelings and thoughts of dependency, being a burden and feeling useless. State of health would probably play a part in this as well. This seems to imply that the questionnaire maybe pathologising normal aspects of peoples' illness experiences. Some of the participants found question seven of the AIS particularly hard to answer, most had to read it a number of times, some questioned the point of it, that is, its relevance to acceptance.

TABLE 1

Figure 2

| Participant Number | AIS      |                        | IIRS     |                        |
|--------------------|----------|------------------------|----------|------------------------|
|                    | Patients | Relatives/<br>Partners | Patients | Relatives/<br>Partners |
| 1                  | 34       | 33                     | 24       | 23                     |
| 2                  | 30       | -                      | 22       | -                      |
| 3                  | *16      | 20                     | 37       | 36                     |
| 4                  | *21      | 25                     | 38       | 40                     |
| 5                  | 36       | 34                     | 16       | 17                     |
| 6                  | 31       | -                      | 31       | -                      |
| 7                  | *23      | 26                     | 18       | 17                     |
| 8                  | 31       | -                      | 23       | -                      |
| 9                  | 23       | 31                     | 19       | 26                     |
| 10                 | 33       | -                      | 14       | -                      |

**TABLE 1.** The scores obtained from the AIS scale and the IIRS scale by ESRF patients and their relatives/partners interviewed in this study. The participant number refers to the patient and their respective family/partner. The scores for the AIS scale range from 8 (extremely low acceptance/adjustment) to 40 (extremely high acceptance/adjustment). The scores for the IIRS scale range from 12 (low intrusion) to 84 (extremely high intrusion) see Methodology section 2.8.1. Participants identified in this study as resigned acceptors are indicated with an asterisk (\*).

There was a general feeling that the scale focused on negative aspects of illness and in this way was not very 'friendly'.

Scores on the IIRS reflected differences between active acceptors and resigned acceptors with resigned acceptors finding illness more intrusive. However they also experienced quite debilitating symptoms.

Again patients found it difficult to comment on this scale, but generally they felt the questions that related to self expression and community involvement irrelevant to their lives.

Scores on both questionnaires from patients and their relatives/partners showed a high degree of concordance. This was also reflected in the verbal reports from relatives/partners.

**DISCUSSION****4.0 PREFACE**

The aim of this study was to develop a theoretical framework with which to understand adjustment to ESRF. In order to do this the conceptualisations of adjustment held by patients with ESRF were explored, and to a lesser extent, those of the home dialysis nursing staff involved in their care, their partners and relatives. From these conceptualisations the researcher applied Grounded Theory techniques to help generate increasingly abstract categories to explain the data. This involved unpacking the meanings contained in the participants accounts through a process of interpretative engagement but also keeping close to the data.

In addition this study also aimed to explore the influence that the length of time on treatment had on conceptualisations, by recruiting samples of patients who were six weeks and twelve months into treatment.

The first section of this discussion will focus on the research findings of this study. These will be considered in relation to the research questions posed and the literature previously described in the introduction. Following in the tradition of previous qualitative studies, additional research will be cited where its relevance has emerged as this study proceeded.

The second part of this discussion will consider the limitations of this study, the clinical implications of the findings and possible directions for future research.

## **4.1 CONCEPTUALISATIONS OF ADJUSTMENT**

This section will discuss the main research question addressed at the beginning of the study, namely conceptualisations of adjustment.

### **4.1.2 TAKING ON BOARD A NEW APPROACH TO BEING AND LIVING**

The core category identified in the analysis was **taking on board a new approach to being and living**. Incorporated within this category was the ability of participants to **accept their illness**. Acceptance comprised emotional, cognitive and behavioural components and participants varied in which components they emphasised. For example some would talk about acceptance in terms of what they did, such as the treatment (behaviour), while others emphasised their positive mood (affective). Participants seemed to feel that the ability to accept illness at an emotional and cognitive level then led to behavioural manifestations of acceptance. This, in part, is consistent with cognitive theory that states peoples' beliefs about the world influence their affect and behaviour. These beliefs manifest themselves in consciousness as automatic thoughts.

Nursing staff in this study also highlighted the possibility of a discordance between these three components (cognitive, emotional and behavioural), specifically that patients could be behaving in a way that suggested acceptance, such as going back to work but at an emotional level they were not accepting their illness. Indirect evidence for such a phenomenon comes from the work of Rachman and Hodgson (1974). They developed the construct of desynchrony while examining responses to behavioural treatments for phobias. Their findings suggested that affective and behaviour changes do not occur simultaneously. Thus cognitive, behavioural and affective changes may occur at different rates to each

other. This concept of desynchrony could be developed in future research that explores the adjustment process.

From this study an important distinction was identified in the analysis between participants who were active acceptors and those who were resigned acceptors. It became clear that the former were characterised by a spirited and determined attitude to their illness. This was reflected in their behaviour, in that they would be more likely to not let their illness and treatment interfere with their life. Furthermore in doing so they ensured that both their illness and treatment were **'contained.'** They were also more likely to emphasise that they did not let treatment rule their life. In contrast the latter were more likely to submit to their illness and let it dominate their existence. Scores on the IIRS also reflected this distinction with resigned acceptors reporting that their illness was more intrusive in various domains of their life.

Several reasons can be postulated to explain why some participants let their illness dominate their life and others did not. For example it seemed that an important factor involved in differentiating active and resigned acceptors was a person's reported physical state of health, with those experiencing more health difficulties tending to be more resigned in their acceptance. Also for the less well participants the uncertainty of how they were going to feel from day to day limited their ability to plan ahead. As fewer and fewer activities were undertaken and more pleasurable activities were curtailed it is easy to see how illness could begin to dominate life. The motivation to try and do things also seemed to be lacking and in this way it was felt the participants could be leading more restricting lives than they need be. For example it did not occur to one participant who loved to go and sit in her garden in the summer, but no longer did so in case she fell asleep and missed an exchange, to take a timer out to ensure this did not happen. A further hypothesis is that

in limiting what they do, participants are trying to protect themselves from further deterioration but in effect they are losing part of the non illness identity. It could be envisaged that eventually identity becomes defined by illness and treatment.

Some of the above hypotheses are consistent with the work and findings of Charmaz (1983). (Her work is discussed in more detail in the section **Experiencing loss**). She explores the process of 'loss of self' in relation to chronic illness. She found that in her sample, participants did lead restricting lives. Of particular interest is her comment that the chronically ill tend to judge themselves by yardsticks applied to the healthy and the able. In this way, she argues, they can set themselves up to lead more restricted lives. Charmaz (1983) identified that living a restricted life fosters an "all consuming retreat" into illness where illness becomes the focus of concern and dominates existence. This is consistent with the findings noted above.

Thus it has been hypothesised that sometimes participants allow their illness to intrude into their life, as a result of a number of different processes that are not directly related to physical health. This could have been tested by extending the sampling to more individuals who had physical problems, but time did not allow this in the present study.

For the active acceptors they seemed to resist getting caught in the spiralling effects of a restricting illness. What actually determines why they could cope with the illness in this way is not clear. A range of explanations could be involved including general coping ability, pre-illness factors and family support. No conclusions can be drawn here but such variables could be explored in future research.

These two styles of acceptance: resigned and active, have not been identified in previous literature on adjustment to ESRF and they certainly warrant further investigation. They are however, to some extent, consistent with the work of Greer *et al.*, (1988) on responses

to cancer. They identified five reactions, fighting spirit, helplessness, anxious preoccupation, fatalism (stoic acceptance), and avoidance (denial). Of these, 'Stoic acceptance', characterised by acceptance of the illness but with a fatalistic attitude, seems to be related to resigned acceptance, and 'fighting spirit' characterised by a determined attitude to fight the illness, seek information about it and adopt an optimistic attitude, seemed in part to correspond with active acceptors. Greer *et al.*, (1979) has found that these are related to outcome. They examined patients' coping style three months post operatively. These were then related to outcome five years later. They found a more favourable outcome (recurrence free survival) was associated with patients whose responses were categorised as denial or fighting spirit than in the patients categorised as showing stoic acceptance or helplessness. Although there are differences in the illnesses explored in Greer's study and this study, future research could expand on the styles identified here and look at their effect on outcome.

In summary this section has discussed acceptance of illness which forms part of the core category. Two main styles of acceptance have been identified and the discussion has focused on possible reasons for these differences and their relationship to past literature.

### **4.1.3 GETTING BACK TO LIFE AND MAKING ADAPTATIONS**

As mentioned above, once participants were able to **Accept** their illness this appeared to set in motion the processes of **getting back to life**. Participants attempted to **re-establish roles and activities**. The type of activity and roles varied and for some participants returning to work was an important priority. This is consistent with studies such as Kaplan De Nour *et al.*, (1976) and Goldberg *et al.*, (1973) (cited by Levenson *et al.*, 1991) who used this criterion 'return to work' as an indication of adjustment. However this goal was

not true for all the participants as some needed to or chose to give up their jobs.

Furthermore it was stated in the analysis section that in some cases if people had other areas of their life that they were able to retain, it seemed to negate the possible detrimental effects of having to give up certain valued roles and activities. By focusing on these retained roles, it can be hypothesised that it served an adaptive function in that it helped to protect them from the upset of relinquishing certain areas of their life.

In some ways the above hypothesis is consistent with Taylor's theory of cognitive adaptation (1983). Her theory states that when people are confronted with life threatening events they respond with cognitively adaptive efforts that may enable them to return to or transcend their previous level of psychological functioning. The themes in which such processes occur include a search for meaning in the illness, attempts to gain mastery of the illness and endeavours to enhance the self. Of relevance to the above is the theme of 'attempts to regain mastery'. Taylor states that one way this is achieved is by a person being able to feel that he/she is exerting control over threat-related events. This control can be an illusory control but helps a person adapt to their illness. Taylor cites the cognitive disconfirmation theory to help explain why people, when faced with a block to their control, manage to still adjust. This theory asserts that people will give up attempting to control areas that they no longer are able to and will turn to other areas of their life that they can exert control over such as treatment. In this way they help protect themselves from an uncontrollable world and blocks do not bring about emotional turmoil. For those participants in this study whose path was blocked by others such as employers, the threat to self esteem and feelings of being stigmatised may have been too much for them to be able to brush aside. Thus it was harder for them to make a switch to other areas of their life.

As participants strove to **get back to living** they realised that some modifications would be needed to the way they did and thought about things. This was encapsulated in the category, **Making adaptations to accommodate illness and treatment**. Failure to make such adaptations could be hypothesised to indicate maladjustment. However it was shown that participants varied in the extent of the adaptations they made, so some made very few and in fact let their treatment rule their life. It also seemed that some of the participants in this study had to make more adjustments maybe because of the nature of their previous lifestyle or because their health was not good. Obviously for such individuals it may be harder to make these adjustments. Differences in styles of incorporating treatment were noted -those who let it intrude versus those who incorporated it into their lifestyle. This was hypothesised to be related to whether patients were resigned acceptors or active acceptors respectively and is thus discussed in more detail above.

It was interesting that for some participants not being able to do some aspects of their self care regime, such as the epo injection, did not negate them from feeling that they have adjusted well to their illness. This may reflect the general trend of participants to be selective in what they judge within themselves to indicate adjustment.

Within this category **making adaptations**, there were some similarities with previous literature, namely the adaptive tasks present in Moos and Tsu (1977) model developed to understand responses to the crisis of physical illness. The first, illness related adaptive tasks, involved dealing with symptoms such as pain and the special treatments required such as CAPD. These tasks were consonant with patients attempts at **incorporating treatment into their routine**. The second set of tasks which were more general, included maintaining a sense of competence, as well as revising goals and expectations which corresponded to **modifying goal and activities**. Other adaptive tasks such as managing

negative emotions, revising the self image and preparing for an uncertain future were more consonant with the category **experiencing loss**. As Moos (1977) states the relative importance of each task will be dependent upon the individual, so for some the priority may be symptom management whereas for others it may be readjusting some goals.

In summary this section has examined some of the main points from the categories **getting back to life** and **making adaptations**. It has discussed the importance of retaining certain valued roles but the possible adaptive strategies used when this is not possible. Different styles of **incorporating treatment** were identified that were thought to correspond to active and resigned acceptors. While these two processes above emphasise more behavioural and social aspects of adjustment, it is important to also note that adjustment is about a person's emotional and cognitive world. Studies that were mentioned that used single dimensions of adjustment such as return to work, would thus be only capturing one element of adjustment.

#### **4.1.4 COPING SKILLS**

Some of the coping styles identified in this study (see analysis) were consistent with those found in the 'coping with chronic illness' literature in general. For example, **cognitive optimising**, **distraction** and use of **humour** have been already identified.

During this study the question arose about the relationship between coping and adjustment. Previous studies have assumed that differences in coping are the cause of differences in adjustment. However it does not seem as straightforward as this. Felton and Revenson (1984) were the first to address this issue of causality in a longitudinal study of patients suffering from various diseases. Based on their results they proposed a bi directional relationship in which positive feedback cycles developed. Phillip *et al.*, (1990) have also

generated similar findings. This is an area that will need to be explored further, but for this study coping skills have been incorporated into the theoretical framework as bi directionally related to other categories.

The coping strategy labelled in this study, **cognitive optimising**, involved participants making comparisons with others, more specifically comparing themselves to people who are less well off (not financially ) than themselves. This coping style has been identified by Forsyth, Delaney, and Gresham (1984). It could be hypothesised that this bolsters participants' self esteem and self image. There was also some evidence in this analysis of upward comparisons helping participants realise what could be possible.

Making downward comparisons as mentioned above is consistent with Taylor's theory of cognitive adaptation (1983), mentioned earlier. One of the themes she identified around which cognitive adaptation occurs, is attempts to enhance the self. One way she found people achieved this was by drawing downward comparisons. Furthermore she noted that the dimensions for comparisons were carefully selected so that the right mode of comparison was chosen that enabled the person to be better off. For example, someone who felt physically well despite their condition, would pick someone who was experiencing physical health difficulties. However a person who was physically debilitated but who had not had to give up work as they were retired, compared themselves to someone who had had to give up work.

Another coping skill that emerged in this study was participants' ability to find something positive from their illness. For example bringing family closer together or re-evaluating life. These could be interpreted as a way for participants to find some meaning in their illness. Finding meaning in illness, through seeking something positive from the situation, rethinking attitudes and priorities and reorganising life along satisfying lines may, as

suggested by Taylor (1983), be an important part of being able to accept illness. More sampling would be necessary to explore this interesting hypothesis.

In summary, this small section has considered the coping skills identified in this study.

Questions have been asked about the relationship between coping and adjustment. Two coping strategies were discussed which seemed to enable participants to maintain their self esteem and find meaning in their illness.

#### **4.1.5 EXPERIENCING LOSS**

It became apparent during the interviews that while participants tried to regain their life or develop a new life, they also seemed to be processing loss feelings, that is feelings such as sadness, sorrow and anger. Participants did vary in their ability to express these feelings. For those who did not, it could be hypothesised that they either suppress such feelings for fear of negative consequences from staff and family or they had managed to resolve these feelings. For example they may have worked through them after being diagnosed.

However, people at twelve months were still experiencing loss feelings suggesting that they such feelings can be prolonged. This is not surprising because the nature of the illness means that participants are confronted everyday with their loss in the form of the catheter and intrusive treatment regime.

As mentioned in the analysis and discussed in more detail below, people are expected to get on with life and make a recovery of sorts. This is also reflected in the rather scant literature on loss and chronic illness, in which most studies examine the processes mentioned in **getting back to life** such as becoming proficient at self care. However a study by Charmaz (1983), mentioned above, seemed pertinent to the present study.

Charmaz conducted a Grounded Theory analysis on interview scripts from chronically ill

and debilitated patients. The basic premise of her work was that patients experience a loss of self. Their illness leads to a “crumbling away of their former self images”, that is, the positive self images that they have built up, without concurrent developments of new ones. This theme of loss of self is developed through her four identified categories, living a restricted life, social isolation, discredited self and becoming a burden. Of particular relevance to this study are the first and last categories. ‘Living a restricted life’ was discussed above. Charmaz last category, ‘becoming a burden’ was felt to be relevant to participants who were physically less well. Becoming a burden, states Charmaz, means becoming more dependent and immobilised. Becoming a burden typically debases the identity because the person has little power and control over his/her situation and the quality of his/her being. Charmaz identified the worst part about being a burden as the feeling of uselessness. Such feelings are intensified by the patient seeing their relative/partner having to take on their care. This indeed was identified by several of the participants, especially those who were more resigned in their acceptance. Charmaz also states that the more ill a person is, the more their self image crumbles and the less they are able to maintain relationships. If they reveal their suffering, show anger or guilt etc., they risk further alienation from those who take an interest in them. This may help explain why some of the participants in this study did not seem to want to express their more negative emotions.

Charmaz’s (1983) work provides some more insight into possible ways of interpreting experiences of loss for the participants in this study.

Other literature on bereavement are also consonant with the findings of this study. A recent model developed to understand responses to bereavement has been proposed by Stroebe and Schut (1995). It has been called the dual process theory. It was developed

after the findings of a number of studies called into question the grief work hypothesis, which states that working through losses is both a necessary and important part of uncomplicated grief. Instead they found that it may not always be effective nor was the avoidance of it deleterious. Their dual process theory extends the grief work hypothesis rather than discounts it, by incorporating behaviour, cognitive and social outcomes of grief, not just affective as emphasised in the grief work paradigm. The model states that adapting to loss involves two parallel processes, loss orientated and restoration orientated coping. Loss orientated coping involves the grief work, namely rumination, yearning, thinking about losses, talking about the loss and trying to accept old roles that have gone for good. Restoration orientated coping refers to adjustments needed at the cognitive and behavioural levels. In relation to bereavement this includes forming a new role and coping with changes in daily life brought about by the loss, such as having to do activities once undertaken by the deceased. It also encompasses learning to do things differently and learning to go places alone. It may involve the mechanisms of denial, repression and suppression of the psychological impact of the loss. Thus these are tasks that are not directly linked with emotional adjustment to loss but they too have to be undertaken. They are closely linked with grief in that as they are performed to both distract a person but also serve as reminders of loss. This introduces a concept central to this model which is the process of oscillation. It is hypothesised that bereaved people move between loss and restoration orientated coping, and that this can sometimes work as a regulatory process. This serves an adaptive function because, as Stroebe and Schut (1995) assert, a person cannot avoid grief but equally cannot be consumed by it without costs to psychological and physical well being. Confronting grief can thus be a tiring process yet it is necessary to do both -that is cope with loss and restoration. The authors have incorporated a time frame

asserting that there is more loss-orientated coping in the early stages of grief but a move towards restoration orientated coping as time goes by.

The model helps to explain both normal and pathological responses of grief. The model is also applicable to other types of losses and chronic illness is an example of this. Certainly the framework presented in the findings of this study is consonant with this and could lead to the hypothesis that participants oscillate between loss orientated coping-**experiencing losses** and restoration orientated coping-**getting back to life and adapting**. This may also explain why at times affective responses maybe be lagging behind behavioural, as in **getting back to life**. The model may also be applicable to the diagnosis stage and the period of time before predialysis.

Another concept that would appear to have direct relevance to this work is chronic sorrow, which was developed by Olshanky (1962). He developed this concept from his work with parents who had given birth to disabled children. He found that they exhibited a continuing grief reaction and he felt that the tasks of mourning with their implicit final recovery stage was absent from these parents. Instead he found that they faced their grief everyday and he applied the concept of chronic sorrow to describe the intermittent and pervasive sadness that confronted them. Chronic sorrow differs from pathological grief and depression in many ways, for example it does not paralyse people, they can function normally, get on with their life and feel fine for the majority of the time but intermittently they experience grief feelings such as sorrow and anger. Further work by Burke *et al.*, (1992) has identified that chronic sorrow is a significant feature of people who have chronic illnesses. They studied the effects of chronicity on a number of different conditions including multiple sclerosis, Parkinson's disease and cancer. They concluded that more than three quarters or more of the people studied experienced chronic sorrow.

The concept of chronic sorrow helps to explain the point made in the analysis that participants at twelve months are still experiencing loss feelings, but these are not paralysing or disabling them to the extent that they are unable to function.

In summary this section has explored the category of **experiencing loss**. Chronic illness entails many losses from body parts to roles. Furthermore the participants in this study were confronted with some of their losses everyday. New literature on loss in chronic illness and loss in general was introduced and its relevance to this study highlighted. In particular a dual process model that encompasses loss orientated and restoration orientated coping was thought to be a useful framework for understanding some of the processes found in this study.

#### **4.1.6 INTERVENING CONDITIONS**

This study has highlighted a host of intervening conditions that could bare on the adjustment process and peoples' conceptualisations of adjustment. Some of these have rarely been considered within the adjustment literature or have been controlled for. Some of these will briefly be considered below.

Firstly there were illness related factors such as the severity of illness, extent of physical symptoms, whether a person was given warning of their condition or presented acutely and whether there was more than one condition present. Secondly there were external influences such as cultural and societal factors. Some participants in this study were the object of others negative stereotypes and stigma. This was especially so in the work situation, where a participant for example had his hours reduced when he felt very able to continue. One can imagine the frustration he felt. Some other studies have also found negative biases and stigma a feature for those with chronic illness (Wright 1988, Susman

1994 cited in Devins *et al.*, 1996) and that such negative stereotypes can lead to significant barriers to vocational rehabilitation or opportunities for employment (Devins *et al.*, 1996). Sex role stereotypes were also, in this study, suggested as possible influences on a persons' adjustment. For example for some male participants work was a very important priority for them and thus their adjustment was framed within this accomplishment. Another participant emphasised her ability to continue with the housework and another vented her frustration because her husband had to do it and it was her role.

Society also has certain expectations on us. For example we live in a society that emphasises individualism thus we value independence and self sufficiency. Within illness experiences this emphasis manifests itself in various ways. For example CAPD is a treatment that is the responsibility of the patient. There is an emphasis on maintaining a normal life or returning to one after illness. As Charmaz (1983) states, this becomes 'the symbol of a valued self'. The emphasis is on pulling through and in this way illness is seen as being a temporary disruption to self rather than causing continued 'loss of self'. Hence others realisation of losses tends to be absent.

This study highlighted that the emphasis was on getting on with life. Goffman (1952 cited in Frank 1992) however would refer to those who encourage this as 'coolers'. By this he means the process whereby people are convinced to accept and adjust to all sorts of losses. As he argues the sick role still dominates much of our thinking, so people are given permission to be sick and given some time to withdraw but there is eventually the obligation to engage in some 'getting better'. While the researcher is not suggesting that participants wallow in self pity it could perhaps be that suffering and loss are not allowed or sufficiently considered. This was highlighted by a participant who recounted how her GP

had wanted to give her antidepressants when she wanted to experience her feelings, not mollify them.

Thirdly, internal influences such as personality factors may also play a part in influencing adjustment and conceptualisations. This was mentioned by some of the participants who felt that a positive attitude was a character trait. Although this is a very under investigated area some work has been undertaken. For example Carver *et al.*, (1989) has looked at dispositional optimism in coping and McCrea *et al.*'s (1986) work suggests a number of common coping styles maybe a measure of personality such as neuroticism.

In summary this section has speculated on a number of intervening conditions that could bare on the process and conceptualisation of adjustment. Again many of these warrant further investigation.

The remaining research questions to be answered by this study address more specific differences in conceptualisations as well as comparing subjective comments to objective measures of adjustment. These will be now be considered below.

## **4.2 DIFFERENCES IN CONCEPTUALISATIONS OF ADJUSTMENT**

The emphasis of this study fell on patients, however, nursing staff were also asked about their conceptualisations. Time did not allow a complete Grounded Theory analysis of nursing staff or the patients' relatives/partners' transcripts and so comparisons have been made at a more thematic level.

This study found that generally there was a high degree of concordance between nursing staff and patients. Nursing staff emphasised the importance of being able to accept illness as a catalyst for other processes, such as resuming previous lifestyles and making modifications. Both nurses (and patients) agreed that feeling physically better was

important in facilitating adjustment. They were particularly keen to point out that adjustment was not just about compliance or returning to work which has previously been used to measure adjustment but that a patient's whole lifestyle needed to be considered. When considering adjustment nurses emphasised the fact that they would respect patients' choices and decisions but were equally sensitive to the problem of using their own ideas about adjustment as a benchmark for judging their clients. For example, those patients who accepted their illness in a more resigned fashion were not necessarily considered by the nurses to have adjusted well to their illness.

Nursing staff also perceived that there would be differences between how medical staff and how patients construed adjustment. They perceived that the medical staff would look at single dimensional or particular indications of adjustment, such as compliance or return to work and may neglect the emotional effects such as feelings of loss. Interviews with the medical staff would have to be undertaken to test this hypothesis further.

In addition to the above, the nurses interviewed felt that their knowledge of the client was more comprehensive because they had more client contact and they visited them in their homes. In view of this they were sensitive to the possibility of desynchrony between behavioural and cognitive elements of adjustment.

Concordances in conceptualisations were generally noted also in relation to the patients' relatives/partners. However some relatives felt that their relative/partner on CAPD were living unnecessary restricted lives. This phenomenon was discussed previously (**getting back to life**).

Interestingly, patients' and partners' AIS and IIRS scores showed a high degree of concordance. Although statistical analysis was not performed and just over half of the participants' relative/partners were interviewed. It does tentatively suggest that

partners/relatives are in touch with the feelings and thoughts of the CAPD patient.

Possibly the illness has brought them closer together, as commented by some participants (see analysis).

The influence of length of time on treatment was also identified as an initial research question. The theoretical framework developed in this study encompassed the views of both patients who had been on treatment for six weeks and those who had been treated for twelve months, however some subtle differences did emerge during the latter stages of the analysis. It seemed that those who had been on treatment for six weeks were still assessing their health or marvelling about their health and finding out their limitations, although this was not always the case. Twelve months after beginning treatment patients were further ahead in areas such as **getting back to life** and **adapting** because they had had more time to develop coping strategies and realise the full ramifications of the impact that their illness would have on their lives.

Some differences were also noted in the category, **experiencing loss**, specifically those at six weeks were more likely to be focused on their loss of body parts whereas those at twelve months seemed more concerned with activities that they missed doing. This makes intuitive sense as newly dialysing patients would be getting used to their new body image and the focus would be on this, whereas for those who had received prolonged treatment, they would have time to realise the full impact that their illness was going to have on their lives. However there was an exception to this and this questions whether feelings of loss about body image may be a gender issue, specifically an issue for some females.

Conclusions can only be tentative and would need to be explored further by increasing the sampling.

**Acceptance of illness** was shown in this sample not to be a function of time. Although those who had been on treatment for twelve months reflected that it had taken a couple of months at least to accept their illness, those who had been on it for six weeks also felt that they had accepted it. It could be argued that the cross sectional nature of this study could lead to such a conclusion where those at twelve months may have had more debilitating, serious problems initially or alternatively their retrospective reporting may be inaccurate. This highlights the need for a longitudinal study with a within subjects design to be able to explore this issue further.

Gender was an issue for data collection to ensure the sample were representative rather than a specific interest of the research. However the researcher did find that the females interviewed found it much easier to talk in general about the issues raised in the interview and about the emotional consequences of their condition compared with the men, who were more concerned with the functional nature of their recovery. This would seem to be consistent with research that has examined gender differences in coping. For example problem focused coping strategies such as analytic, task orientated coping styles have been found to be more prolific amongst men (Folkman Lazarus 1980, Billings and Moos 1981 cited by Stroebe and Schut 1995). In contrast, women are found to use more emotion focused coping strategies such as the expression of emotion and seeking support.

### **4.3 COMMENT ON AIS AND IIRS SCORES**

The results of this study found that the AIS scores sometimes did not reflect subjective reporting of acceptance. This was particularly so for those participants who were more resigned in their acceptance.

The questions that enquired about feelings of dependency, being a burden, feeling useless and missing things that used to be accomplished (questions, 2,3,4,5) were answered in the affirmative by these participants. These feelings reflected their illness experiences but did not negate them from feeling that they had accepted their illness.

The questionnaire has not defined before hand what it meant by acceptance, but from the questions asked one could assume that it must be based on the premise that feelings of uselessness, being a burden etc. are negative and detract someone from being able to accept their illness. However it seems that for some patients these feelings are normal.

Some participants felt that the questions were “too negative and unfriendly”, with only one positive statement incorporated.

Acceptance for this sample of people was defined in cognitive, emotional and behavioural terms and this is not captured in the questions from the questionnaire.

Scores on the IIRS also seemed to reflect the differences between active and resigned acceptors with resigned acceptors reporting higher intrusiveness ratings. However this was also the case for the physically less well.

It can be seen that the peripheral questions posed at the beginning of the study can only be tentatively answered because of the sample size but they do provide much material for future research.

#### **4.4 CONTRIBUTION TO RESEARCH**

The ambitious goal of providing a comprehensive theoretical framework in which to understand adjustment to ESRF is not fully realised here but as stated in the methodology section, clear categories have been identified that explicate processes involved in adjustment.

The framework presented here (see fig.1) offers a new approach with which to conceptualise adjustment. One that is based on the views of the patients themselves and the staff that work with them. It presents adjustment as a series of interrelated processes and highlights possible factors that would influence these processes from the patients' circumstances and lives. It incorporates cognitive, behavioural, social and affective components and in this way provides a comprehensive framework in which to view adjustment to ESRF. Furthermore the processes identified in this framework have been shown to be consonant with the findings of a number of previous studies.

#### **4.5 EVALUATION OF THIS STUDY**

As mentioned before (see methodology) it is questionable whether research using qualitative approaches can be evaluated in the same way as quantitative research. However issues of generalisability, reliability, reproducibility are important, they are just redefined.

This section will explore these redefinitions, examine how this study attempted to incorporate these and then consider some of the limitations of this study.

*Issues pertaining to generalisability in Grounded Theory approaches* -The purpose of a Grounded Theory is to specify the conditions that give rise to specific sets of actions/interactions related to the phenomenon being studied and which results in particular conditions. It is generalisable to those specific situations only. Of course the more theoretical sampling conducted the more conditions, dimensions will be incorporated into the study and generalising will be greater. However where new research highlights different variations these can then be further incorporated into the original formulation, as amendments (Strauss and Corbin 1990). Rennie *et al.*, (1988) states that "It is intimacy

with the phenomenon that Grounded Theorists seek much more than external criteria of adequacy such as hard evidence of generalisability derived from a random sample of a large number of individuals” p147.

*Issues pertaining to reliability-* The issue of reliability is different as Qualitative research strives to make sense of the world, not through objectivity but to gain an understanding of the views and meanings of the participants.

*Issues pertaining to validity-* Qualitative research is based on the premise that there is no objective reality against which research findings can be measured. Each piece of research is thus situated within a participant’s context and relates to the worlds of the participants.

*Issues pertaining to reproducibility-* Strauss and Corbin (1990) point out that Grounded Theory denotes reproducibility by stating that given the same theoretical perspective of the original researcher and following rules and procedures for collecting and analysing the data and a similar set of conditions, another researcher should meet the same phenomenon.

Charmaz (1990) however has pointed out that the situation is more complicated than this in that a researcher must have a perspective that he/she brings along when analysing the data.

Some of the ways of trying to ensure that the above issues are addressed in the research are in fact built into the Grounded theory method. For example the researcher attempted to keep close to the data by using the constant comparison method. The researcher made every attempt to saturate categories, that is filling, supporting and providing repeated evidence for the categories.

Theoretical sampling whereby analysis alternates with the data gathered, (in qualitative research sampling is driven by theoretical concerns rather than sampling multiple cases) however was not possible in the time available for this study.

Triangulation, by using different sources to provide information, was used by the researcher, thus interviews were undertaken with nursing staff, patients and patients' relatives/partners. There were also peer examination of the codes and categories in a weekly support group.

#### **4.6 AREAS OF DIFFICULTY**

*Verbal reports*-The findings of Grounded Theory rest on the verbal reports of the participants. This has been challenged by a number authors (Nisbett and Wilson cited by Rennie *et al.*, 1988) for various reasons. For example it has been argued that the researcher may not gain access to internal processes of which participants are unaware (Rennie *et al.*, 1988). In short the absence of external criteria for judging the accuracy of patients' reports makes it impossible to test the accuracy of verbal reports. However, use of the constant comparative method to illustrate that participants report similar things and triangulation (as in this study) can increase the credibility of verbal reports.

*Respondent validity*-As previously mentioned (see methodology) respondent validity involves taking the findings back to the participants for verification and validation. This is a contentious area, as highlighted previously. There was insufficient time to perform respondent validation in this study and so the findings were presented and validated with a Clinical Psychologist working in renal care. Presentations to nursing staff and consultants are planned for the future to further validate the findings of this study.

*Researcher bias*-This was mentioned in the methodology section so that the reader can judge for themselves the part played by the researcher's own beliefs.

*The interviews*- Some participants found it very difficult to access thoughts and feelings about adjustment. The researcher found that the men interviewed found it especially

difficult, seeming to be more comfortable with discussing the practicalities of illness and treatment. The women tended to be more descriptive and engaged in self reflection about the impact of their illness.

## **4.7 CLINICAL IMPLICATIONS**

As stated above (section 4.5), the generalisability of the findings in this study to other situations is dependent on the conditions and the context of these studies being similar. Indeed some authors such as Lincoln and Guba (1985) have argued that the transferability of the findings from qualitative studies is more the responsibility of the person wanting to transfer the findings, rather than the authors, to ascertain the relevance of them. However, this study has not adopted this more radical position and will explore some of the clinical implications of this study.

The findings have implications for both direct psychological work with individuals with ESRF and medical staff in general. Both of these will now be considered.

### **4.7.1 PSYCHOLOGICAL WORK**

This study has highlighted that loss can be a feature of chronic illness and furthermore a natural part of the adjustment process. The importance of allowing patients to have such feelings was highlighted in section 4.1.6. In particular the concept ‘chronic sorrow’ was thought to be relevant to the findings. This type of loss characterised by a pervasive but intermittent sadness, can be differentiated from pathological grief/loss which would indicate that a person was experiencing difficulties in adjusting to their illness. Clinical Psychologists involved in providing a service to renal patients are in a position to validate and recognise these loss feelings as well as identify more pathological loss that may warrant

intervention. Clinical Psychologists could also play an important role in providing information about loss to other professionals. This is important because if other professionals such as Consultant nephrologists are able to identify that anger and sorrow maybe a long term feature of a patient's reaction to their illness, this may help guard against labelling patients and interpreting such reactions as indicative of an inability to come to terms with his/her condition.

Feelings of loss maybe particularly evident upon diagnosis of ESRF. For example, one of the participants in this study described this time as being particularly difficult. She felt that hospital visits were only attending to her physiological state and that feelings were rarely explored. She would have valued some help in understanding her feelings and exploring her fears. Clinical Psychologists are already becoming involved in pre-dialysis clinics and so it would be feasible for them to become involved earlier on in the treatment schedule.

This could also have a knock on effect because if patients were made aware of psychological services and also psychological issues arising from their illness at that point, it may increase the likelihood that they will more responsive to seeking help when it is needed. This is important because nurses had reported that the mere mention of seeing a psychologist to some patients has been greeted with shock as they assumed and feared that others thought they were 'mad'.

The distinction and possible desynchrony suggested between behavioural, cognitive and emotional correlates of adjustment, identified in this study, would seem to have important clinical implications for both Psychologists and medical staff. It could not only inform the psychological assessment but it would seem particularly important that nursing staff who, in general, have more frequent contact with patients and who are likely to be referring to Clinical Psychologists, are aware of this. For example any desynchrony between

behavioural and emotional aspects of adjustment may be particularly difficult to pick up when the main focus of nursing work could be directed at the procedural and technical aspects of treatment. Clinical Psychologists are in a position to furnish medical staff with such information through the vehicle of training/educational days or consultancy situations.

The coping strategies identified in this study would also seem to have important clinical implications. This study highlighted that participants used various strategies to help them cope with their illness and treatment including **cognitive optimising, humour and distraction**. Some of these were purposeful but some were reflexive. Such techniques appeared to help participants **modify goals and activities make adaptations to accommodate illness and treatment** and generally **get back to life**. These are useful strategies to be incorporated into any intervention offered that focuses on adjustment but particularly for interventions based on a cognitive behavioural model.

Another clinical implication arises from the distinction between active acceptors and resigned acceptors identified and highlighted in this study. Such a distinction would seem to be useful in assessment and intervention. Particularly notable is the process by which treatment and illness become increasingly prioritised while other aspects of life are relinquished. Along with this, the processes of **adapting life and modifying goals and activities** becomes a very low priority. This maybe useful in both assessment and psychological intervention.

The participants' comments about the AIS and their scores, also have implications. Such a tool has not been found to be particularly user friendly, even pathologising some peoples normal experiences. While the simplicity of the AIS is attractive, this study questions its validity with regard to measuring acceptance in patients with ESRF.

Future studies which build on the framework offered in this study should lead to the development of a quantitative or qualitative adjustment assessment tool. Such a tool would, at present, seem some way off, but it would undoubtedly be of use to psychologists, nephrologists and nursing staff in nephrology clinics. If such a tool were used routinely it would provide a more comprehensive assessment of a patient's functioning. Adjustment difficulties could be identified earlier and a baseline could be provided for future reference. This tool would also be useful in research that explores adjustment to ESRF.

Quantitative studies could be conducted that explore factors effecting adjustment.

Furthermore, consistent use of such an instrument will help to make results across studies more meaningful and comparable. This highlights the usefulness of utilising qualitative methods to develop theory and then quantitative methods to test and validate the theory.

#### **4.7.2 OTHER PROFESSIONALS**

The findings of this study also highlights problems with the approach to patients with ESRF taken for example by nursing staff. Currently there is an emphasis on helping patients fit dialysis into their routine as far as possible rather than organise their lives around their treatment. Videos at the training week paint a 'rosy' picture of life on CAPD with images of people playing sport, such as squash or swimming and showing people at work.

However, the reality for some patients, as highlighted in this study, may be very different.

It could be useful to have 'well adjusted' dialysis patients as role models in the predialysis clinics. They could not only offer a realistic picture of life, but also give insights into the modifications that can be made to help live a life that is not dominated by dialysis. For example, a participant in this study reported that she would have like to have been told that that you are able to undertake a host of activities while dialysing, you do not have to sit in

the bathroom “reading the medicine labels”. This role modelling approach could be extended to a buddy system. In considering this it is also important to note a number of possible problems that could be envisaged using this approach such as the possibility of setting people up for failure. If people like to make downward comparisons then having a well adjusted individual as a buddy, or present at pre-dialysis, may make them feel inadequate if they are unable to attain the same level of adjustment. Despite these problems, the findings of this study suggest this approach would offer a real improvement to ESRF care and is a key area for future research.

Another factor strongly highlighted in this study is that behavioural correlates of adjustment may not necessarily reflect whether someone has adjusted at the emotional and cognitive level. This is an important consideration for all medical staff working in nephrology clinics, again Clinical Psychologists could play an important role in highlighting this and ensuring that cognitive, emotional, social and behavioural aspects of adjustment are considered.

#### **4.8 DIRECTIONS FOR FUTURE RESEARCH**

A number of questions for future research have already been mentioned throughout this discussion. Presented below are further suggestions.

It would seem important to explore the applicability of these findings or indeed extend the sampling to a number of groups within the ESRF population. For example, sampling different age groups and patients who have been on CAPD for longer than twelve months; extending the sampling to the newly diagnosed and those on the path to reaching end stage. There may also be cultural differences in adjustment which would be an important area to explore in view of the multi ethnic population that the nephrology departments serves.

Further sampling like this will reveal more variations and thus the density of the framework presented in this study, will be greater. There will also be wider applicability of the theory because more and different sets of conditions affecting phenomena maybe identified.

Once the theory has been developed further it will be possible to devise an assessment tool that would be an important step in examining factors that effect adjustment, differences in adjustment styles and effects on outcome.

Another important area of investigation is the distinction between active and resigned acceptors. It would be helpful to establish the relationship of this to outcome e.g. adjustment and survival and to explore possible variations within these styles of acceptance which would allow for a more tailored treatment regime.

As stated above, it is acknowledged that a comprehensive theoretical framework with which to understand adjustment to ESRF may not have been attained by this study but it is hoped that the conceptual model presented, here is a first step to achieving this.

Furthermore this model may also have relevance to other chronic illness such as arthritis and diabetes, thus this study may offer a starting block in the development and exploration for a universal theory of adjustment.

**CONCLUSIONS**

Adjustment to ESRF has been the subject of a vast number of studies. However, it has been noted that a clear picture of how people adjust and the process of this adjustment has yet to emerge. The fundamental problem seems to be that these studies have lacked a theoretical conceptualisation of adjustment. This is also partly true of the adjustment literature in general.

This study aimed to explore the conceptualisations of patients who had reached ESRF. It also, to a lesser extent, aimed to examine how these contrasted with those of their relatives or partners and nursing staff involved in their care.

A framework in which to conceptualise adjustment was presented with the key process identified as being **'Taking on board a new approach to being and living.'**

Some of the processes identified within all the categories were consonant with the previous literature but it is argued that the model presented a more comprehensive consideration of adjustment, incorporating social, cognitive, emotional and behavioural facets.

This study concluded with an evaluation of the study and suggestions for future research.

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**APPENDIX 1**

**Interview Guide**

*(History of illness, context)*

Brief History of Kidney problems from when it started to beginning dialysis. (Time scale, feelings upon diagnosis.)

*(Illness experiences)*

What are the main problems with your illness/treatment.

Does it prevent you from doing anything?. Enquire about feelings about this.

What have you lost as a result of your illness?

What have you gained as a result of your illness?

*(personal)*

Do you have any worries for the future?

Do you ever feel down about your illness ?

What do you do when you feel like this?

*(Adjustment)*

What adjustments have you had to make as a result of you illness/treatment?.

Tap into external and internal

What aspects have been harder to adjust to?

What aspects have been easier to adjust to?

Do you feel you have adjusted to you illness?

Expand -Can you say more about that?

If you were not adjusted how would life be different ?.

If you were adjusted how would life be different?

What has helped you adjust?

What has been unhelpful or hindered your adjustment?

# ACCEPTANCE OF ILLNESS SCALE

APPENDIX

## APPENDIX 2

Name: \_\_\_\_\_

Date: \_\_\_\_\_

Record Number: \_\_\_\_\_

### Instructions

Please respond to each of the following items by choosing a number from 1 to 5 on the scale adjacent to the item which you feel best describes you. Then circle the number you have chosen. There are no right answers to any of the questions.

1. I have a hard time adjusting to the limitations of my illness.

Strongly agree      1      2      3      4      5      Strongly disagree

2. Because of my health, I miss the things I like to do most.

Strongly agree      1      2      3      4      5      Strongly disagree

3. My illness makes me feel useless at times.

Strongly agree      1      2      3      4      5      Strongly disagree

4. Health problems make me more dependent on others than I want to be.

Strongly agree      1      2      3      4      5      Strongly disagree

5. My illness makes me a burden on my family and friends.

Strongly agree      1      2      3      4      5      Strongly disagree

6. My health does not make me feel inadequate.

Strongly agree      1      2      3      4      5      Strongly disagree

7. I will never be self-sufficient enough to make me happy.

Strongly agree      1      2      3      4      5      Strongly disagree

8. I think people are often uncomfortable being around me because of my illness.

Strongly agree      1      2      3      4      5      Strongly disagree

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# ACCEPTANCE OF ILLNESS SCALE



Name: .....

Date: ..... Record Number: .....

## Instructions

Please respond to each of the following items by choosing a number from 1 to 5 on the scale adjacent to the item which you feel best describes you. Then **circle** the number you have chosen. There are no right answers to any of the questions.

**1. I have a hard time adjusting to the limitations of my illness.**

Strongly agree      1                  2                  3                  4                  5                  Strongly disagree

**2. Because of my health, I miss the things I like to do most.**

Strongly agree      1                  2                  3                  4                  5                  Strongly disagree

**3. My illness makes me feel useless at times.**

Strongly agree      1                  2                  3                  4                  5                  Strongly disagree

**4. Health problems make me more dependent on others than I want to be.**

Strongly agree      1                  2                  3                  4                  5                  Strongly disagree

**5. My illness makes me a burden on my family and friends.**

Strongly agree      1                  2                  3                  4                  5                  Strongly disagree

**6. My health does not make me feel inadequate.**

Strongly agree      1                  2                  3                  4                  5                  Strongly disagree

**7. I will never be self-sufficient enough to make me happy.**

Strongly agree      1                  2                  3                  4                  5                  Strongly disagree

**8. I think people are often uncomfortable being around me because of my illness.**

Strongly agree      1                  2                  3                  4                  5                  Strongly disagree

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# IIRS

**INSTRUCTIONS:** The following items ask about how much your illness *and/or* its treatment interfere with different aspects of your life. Please circle the number that best describes your current life situation. If an item is not applicable, please circle the number 1 to indicate that this aspect of your life is not affected very much. Please do not leave any item unanswered.

**How much does your illness and/or its treatment interfere with:**

1. HEALTH

*Not very much*      1      2      3      4      5      6      7      *Very much*

2. DIET (i.e. the things you eat and drink)

*Not very much*      1      2      3      4      5      6      7      *Very much*

3. WORK

*Not very much*      1      2      3      4      5      6      7      *Very much*

4. ACTIVE RECREATION (e.g. sports)

*Not very much*      1      2      3      4      5      6      7      *Very much*

5. PASSIVE RECREATION (e.g. reading, listening to music)

*Not very much*      1      2      3      4      5      6      7      *Very much*

6. FINANCIAL SITUATION

*Not very much*      1      2      3      4      5      6      7      *Very much*

7. RELATIONSHIP WITH YOUR SPOUSE / PARTNER

*Not very much*      1      2      3      4      5      6      7      *Very much*

8. SEX LIFE

*Not very much*      1      2      3      4      5      6      7      *Very much*

9. FAMILY RELATIONS

*Not very much*      1      2      3      4      5      6      7      *Very much*

please turn over ...

**How much does your illness and/or its treatment interfere with:**

**10. OTHER SOCIAL RELATIONS**

*Not very much*      1      2      3      4      5      6      7      *Very much*

**11. SELF-EXPRESSION / SELF-IMPROVEMENT**

*Not very much*      1      2      3      4      5      6      7      *Very much*

**12. RELIGIOUS EXPRESSION**

*Not very much*      1      2      3      4      5      6      7      *Very much*

**13. COMMUNITY AND CIVIC INVOLVEMENT**

*Not very much*      1      2      3      4      5      6      7      *Very much*

Please check that you have answered ALL of the items. Thank you for helping us with our research.

**APPENDIX 3****OPEN CODING****Paragraph Four.**

maintaining normality  
resists ills  
treatment encroaching on time.  
predicting difficulties under different circumstances

**Paragraph five**

redefines illness  
illness effects  
others adjusting to it  
perceives others as not accepting  
perceives others understanding of illness as different

**Paragraph six**

Illness identity  
differing perceptions of illness  
time frame differences  
interpreting images of self given by others.

**Paragraph seven**

threat to self  
overt demonstration to others  
challenge others perceptions

**Paragraph eight**

work role reduced  
importance of work  
powerless position

**Paragraph nine**

acceptance of illness  
acceptance of treatment  
maintaining normality  
fit treatment into lifestyle  
minimal life changes required  
variable low mood  
physical symptoms

**Paragraph ten**

procedures on treatment regime  
changes in self-body parts

resigned in acceptance  
changes to self  
loss of wholeness  
fit treatment into routine

Int-What adjustments have you had to make since your illness?

Sub-You see I have not had to make too many really I just try and live a normal life.....I try and live as before and not make it a handicap, I do everything I used to do the only reminder is having to do it FOUR TIMES A DAY.....so you loose an hour every time you do it.....but what I do is I manage to work it around. I come home for lunch so that I can do the CAPD .....But I imagine if you were on shift work you would not be able to do that. You would have to find some other way around it. 4

You have NOT GOT TO LET IT AFFECT YOU.... Its a thing that has to be done. I do not think about it as an illness but as a problem. It is no good saying I am not going to do it its a necessity.....Having said that it alters your life as far as work is concerned. It is other people who have problems adjusting. People do not accept that you are trying to have a normal life. they still think that you are poorly. Not family but others. They do not understand dialysis-that's the crunch of it. 5

Which parts do you think they do not understand?

Sub Well it is because you have kidney failure they think that it is that you are on a life line that you are on the way out- but not everybody thinks this.....you know I was in hospital for four weeks before this which is not very long really but they think it is. You know they can straighten anybody out now. But they think I am handicap and sick which of course I am not really. 6

Int Feelings about this ? (*tape distorted*)

Sub-Well I suppose I am a little upset about it.....The fact that they think I cannot do things anymore. I am now having to prove more than others that I can. I can get tired then. 7

They think YOU ARE ALWAYS SICK.....sick all the time but I am not. ITS SO FRUSTRATING. Work is very important part of life and now I do less duties and part time- but what do you do? Cannot rock the boat.....may not want me back!

Int so It sounds like you are in a difficult position.

Sub-YEP. Anyway .....

Int Do you feel you have adjusted to your illness?

8

Sub yes.... I have accepted it.

Int Can you say more about what that means to you?

Sub-Its not about adjusting it is that I have accepted it..... I accept that it has to be done. I lead a normal life as possible and fit that CAPD into my lifestyle. I feel pretty healthy really which is good. Really I have not changed too many things in my life so It is easier to adjust to it. I mean sometimes I do get low about it but you know that does not mean I have not accepted it-the wife will tell you.....You know when you feel ill? Like you often feel colder when you are on it and sometimes you get very tired.

You also have to accept that you have to watch your fluid levels you have to take your medication. So there is a lot of remembering to do and you have to fit in into your routine. You have to accept that this is the way it has to be.

10

You have to accept, I suppose, the exit cite. You do feel that you are not the same person anymore -you have this pipe in your stomach your not a full person anymore. YOU ARE NOT THE SAME as when you went in to hospital.....

Int Can you say more about what you mean by that?

Sub-Well you have gained something that you do not really want but you have accepted it. What you do is your mind goes blank to it.....obviously I am slightly different now cause I have this thing here-a reminder that I do not have kidneys anymore. (Laughs)...Like you are not whole( laughs)

Int Could you say more about that ?