

Perspectives from Consultant Nephrologists and Families on how  
Patients with a Learning Disability Cope with Chronic Kidney  
Disease

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## ABSTRACT

Healthcare for patients with a learning disability is an important topic; one that is receiving increased attention by the media, government, and NHS. Management of chronic illness is also an important topic, prioritised by the Department of Health. There is little research looking at chronic illness and learning disability, and contemporary models of coping and adjustment do not take into account the possible effects of having a learning disability. This research looked at how patients with a learning disability cope with chronic illness and focused specifically upon the experiences of patients with a learning disability diagnosed with *stage V renal failure*. This condition involves making a number of difficult decisions about treatment and adhering to difficult treatment regimes, and is amongst the most intrusive of illnesses in terms of impact upon quality of life.

Five consultant nephrologists and five families/carers were interviewed. The data were analysed using grounded theory. The interviews from the two participant groups were analysed as two separate groups, and two models emerged from the data describing how individuals with a learning disability may cope with kidney disease.

The results showed a complicated relationship between the level of learning disability and coping. Other factors unique to the individual (such as their previous experiences), the level and type of support the patient has, and their experiences of hospital care (including the role of the consultant) are all additional important factors that can affect coping.

The research findings are related to the literature, and possible clinical implications are discussed. Future areas of research are suggested.

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## 1.0 Introduction

Healthcare for patients with a learning disability is an important topic, one that is receiving increased attention in the NHS, and by the media and government. Several investigations and reports have been published over the past decade, as serious issues regarding the inequalities in healthcare experienced by patients with a learning disability have come to light. The Yorkshire and Humber Strategic Health Authority has named improving the health services for those with a learning disability a priority (Yorkshire and the Humber Strategic Health Authority 2007, 2009 & 2010). Several reports (for example Treat Me Right! Mencap 2004, and Death By Indifference, Mencap 2007) are illustrated by accounts from families of patients with a learning disability, but there are few published studies with a qualitative analysis of accounts regarding this patient group.

This research looks at how patients with a learning disability cope with chronic health problems, and focuses upon the experiences of patients with a learning disability diagnosed with the chronic illness renal failure (Stage V). This condition involves making a number of difficult decisions and adhering to difficult treatment regimes, and is amongst the most intrusive of illnesses in terms of detrimental effects upon quality of life. The renal service at the Teaching Hospitals NHS Trust is the largest renal service in the United Kingdom, and the staff there expressed interest in and enthusiasm for carrying out such research within their department.

Due to the small evidence base, there is little understanding of how patients with a learning disability cope with a chronic illness and its treatment, such as renal failure and dialysis. As such, qualitative research was the best way to begin looking at this area. Initially, the researcher planned to interview five patients with a learning disability diagnosed with chronic kidney disease and five Consultant Nephrologists.



Medical consultants have responsibility for patients under their care. Whether or not they believe a patient will be able to cope with difficult treatment regimes will have important implications as to whether that patient is offered that treatment. Therefore, the consultants' accounts of how patients with a learning disability cope with chronic kidney disease and its treatments are very important. Despite efforts to recruit patients, only two agreed to participate, and in fact it was the parents of these patients that had wanted to take part on behalf of their child. Due to the lack of appropriate patient recruitments, ethical approval was sought to interview the families and carers of patients; if it was not possible to interview the patients themselves, then the interviewing of family was hoped to be the next best way of obtaining the patient's story. Five families/carers were interviewed.

The data were analysed using grounded theory. Grounded theory was deemed the best method of analysis because themes are generated by the researcher from the data. It is theory-building in nature and two models have emerged from the data through the analysis, describing how individuals with a learning disability may cope with kidney disease.

## **2.0 Review of Definitions, Policy and Literature**

This chapter begins by considering what constitutes chronic illness, kidney disease (or 'renal failure'), and learning disability. Some of the key reports investigating learning disability and health care are considered. The literature review then focuses upon psychological models of coping and adjustment to chronic illness, the specific demands of adjusting to dialysis, and research regarding coping and adjustment to illness with a learning disability.

## 2.1 Definitions

### 2.1.1 Chronic Illness

According to the Department of Health (2004):

“Chronic diseases are diseases which current medical interventions can only control and not cure. The life of a person with a chronic condition is forever altered – there is no return to normal” (p3).

In 2004, the DoH published the finding that 60% of adults in the UK report having a chronic health problem (p4), and that the number of people diagnosed with chronic conditions in the UK continues to rise year after year. They go on to suggest that 45% of individuals with a chronic disease have more than one chronic condition, and that for those aged over 65years, this rises to over 70% (p4). They quote that around 25% of individuals with a chronic condition actually have three or more conditions, making their care and management complex. Chronic illness can have a wide range of effects for both the individual and their family. There are often difficulties with chronic pain, altered mobility and fatigue. Individuals can experience feelings of powerlessness, stigma, and social isolation and they can find it difficult to keep up with work, school and finances. Body image, sexuality and overall quality of life can often be affected.

The 2004 DoH document *Chronic Care Compendium* describes concerns regarding the management of chronic health conditions within the UK, reporting that the day-to-day management and care of individuals with chronic illness is ‘not good enough’ (p10), and that as a result patients are developing unnecessary complications and dying prematurely.

In 2005, the DoH published ‘Supporting People with Long-Term Conditions’. In this report the DoH promotes the use of a Social-Care Model of treating and managing people with chronic, or ‘long-term’, conditions. The DoH describes how historically the treatment of patients with chronic conditions has been reactive, unplanned and

episodic. This has resulted in heavy use of secondary services; for example, only 5% of patients (many with a long-term condition) actually account for 42% of all acute bed days (p5). The DoH believes that a more systematic, effective and personalised approach to their care is needed. The NHS and Social Care Long-Term Conditions Model groups patients and matches their care to their needs. There are three levels: level 1 – supported self-care, level 2 – disease-specific care management, level 3 – case management. The DoH suggests that the immediate focus should be upon providing case management and personalised care plans for the most vulnerable patients with complex long-term conditions. The report strongly recommended the immediate implementation and action of the model by every health and social care organisation, with a view to the care of patients with long-term conditions being planned and personalised instead of reactive and episodic.

The King's Fund inquiry entitled 'Managing People with Long-Term Conditions' (Goodwin, Curry, Naylor, Ross & Duling 2010) investigated the current level of care quality for people with long-term conditions and concluded that:

“Apart from certain indicators developed through the Quality and Outcomes Framework, there is otherwise little data and information to judge current care quality. What evidence does exist suggests that significant improvements have been made in some areas – particularly for diseases such as diabetes, heart failure and chronic obstructive pulmonary disease – but less progress has been made for depression, dementia and arthritis, and these require a more collaborative care model for a higher quality of care to be achieved” (p8).

It is evident that chronic illness is an important and growing issue that affects the lives of many individuals and their families within the UK. This is reflected by the increasing demands placed upon the NHS by the needs of these individuals, and by the growing focus upon improving management and healthcare provision.

### *2.1.2 Renal Failure*

The kidneys filter the blood, removing waste products that are a result of normal bodily functions, and excess fluid. The excess fluid and waste products become urine. If the kidneys begin to fail, the waste products and excess fluid build up in the body resulting in symptoms of fatigue, vomiting, itchy skin and swollen feet, hands and ankles.

Chronic kidney disease (or renal failure) is a long-lasting and irreversible condition that is caused by damage to the kidneys. The most common cause of kidney failure is damage from other chronic conditions, such as diabetes and high blood pressure. Kidney failure is described as having a number of stages. When the kidneys lose almost all functioning, it is known as stage V renal failure, or established or end-stage renal failure (ERF). When a patient reaches stage V there are two treatment options: dialysis or kidney transplant.

There are two forms of dialysis: haemodialysis and peritoneal dialysis. Haemodialysis is the most common, and involves inserting a needle into a blood vessel, which is attached by a tube to a dialysis machine. Blood is transferred from the body through the dialysis machine which filters the blood of the waste products and excess fluid. Haemodialysis typically takes place in a hospital or dialysis unit, and a patient will need this dialysis three times a week. Each session lasts around four hours.

Peritoneal dialysis involves having a catheter inserted through an incision in the abdomen and 'dialysis fluid' is then pumped into the peritoneal cavity. As blood moves through the peritoneum, waste products and excess fluid move from the blood into the dialysis fluid. The fluid is then drained out of the cavity. Peritoneal dialysis does not take place in the hospital. Patients usually require four exchanges a day, or have it using a machine over night.

Kidney transplant can be from a cadaver or from a live donor (usually a relative). The large majority of patients will have had dialysis prior to receiving a transplant. Following transplant, the patient will need to follow a complicated medication regime although dialysis will no longer be needed. Following transplant, there is a risk of the patient's body rejecting the kidney.

### *2.1.3 Learning Disability*

According to Emerson and Hatton (2008) there are estimated to be around 985,000 individuals in England with a learning disability (2% of the population), of which 828,000 are adults. They estimated a modest and sustained growth of 14% over the next two decades in the numbers of people with learning disabilities known to learning disability services (p2).

There are three features that have worldwide recognition in terms of diagnosis and classification that define an individual as having a learning disability (Department of Health, 2001a):

- Significant impairment of intellectual functioning (usually an IQ score of less than 70).
- Significant impairment in adaptive/social functioning.
- Age of onset before adulthood.

There are ongoing issues regarding the idea and label of 'learning disability'; its use and viability as a diagnostic term, and how people with a learning disability feel about it as a label. It remains a conceptual category, but one that is used in organising and delivering care in Health and Social services

## 2.2 Learning Disability and Healthcare Legislation

There has been an increasing number of reports and legislation published over the past decade regarding learning disability and health care including: Valuing People – a New Strategy for Learning Disability for the 21<sup>st</sup> Century (Department of Health, 2001a), Treat Me Right! (Mencap, 2004), Equal Treatment – Closing the Gap (Disability Rights Commission, 2006) and Equal Treatment – Closing the Gap: One Year On (Disability Rights Commission, 2007), Death By Indifference (Mencap, 2007), Investigation into the Service for People with Learning Disabilities Provided by Sutton and Merton Primary Care Trust (Healthcare Commission 2007), Healthcare for All (Michael, 2008), State of Healthcare 2008 (Healthcare Commission, 2008), Valuing People Now (DoH, 2008), and Health Action Planning and Health Facilitation for People with Learning Disabilities: Good Practice Guidance (Department of Health, 2009). For the purpose of this review, a number of the key reports are briefly reviewed.

### *2.2.1 Valuing People – a New Strategy for Learning Disability for the 21<sup>st</sup> Century (DoH, 2001a)*

Valuing People was the first white paper to be written for people with a learning disability for thirty years. It is based on four principles; of people having rights as individuals and citizens, for inclusion in the local community, for persons with a learning disability to have real choices, and for there to be real chances and opportunities to be independent.

Valuing People reports that persons with a learning disability have greater health needs than the rest of the population, and are more likely to:

“...experience mental illness and are more prone to chronic health problems, epilepsy, and physical and sensory disabilities. An increasing number of young people with severe and profound disabilities have complex health needs... As life expectancy increases age-related diseases such as stroke, heart disease,

chronic respiratory disease and cancer are likely to be of particular concern. There is an above average death rate among younger people with learning disabilities” (p59).

The paper listed a number of major problems that needed to be worked on, one of which was healthcare:

“When people with learning disabilities approached health care providers for assessment or treatment they often found difficulties in gaining access to the help they needed. The health needs of people with learning disabilities may not be recognised by doctors and care staff who have no experience of working with people who have difficulties in communication. Health outcomes for people with learning disabilities fall short when compared with outcomes for the non-disabled population” (p60).

The report states that few people with learning disabilities access health screenings, that there is inadequate diagnosis and treatment of specific conditions (such as heart disease and osteoporosis), that there is an over-dependence upon psychotropic drug-use with people with challenging behaviour (with poor outcomes as a result), and that healthcare staff can fail to recognise the potential health complications of conditions that can cause learning disability.

As such, Objective 5 of Valuing People is that of “**Good Health:** to enable people with learning disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary” (p26).

### *2.2.2 Treat Me Right! (Mencap, 2004)*

Treat Me Right sought to highlight how people with a learning disability have poorer health and experience inequality when it comes to accessing and receiving healthcare

in comparison to the rest of the population. It illustrated these concerns with stories and reports from families and carers of their loved ones' experiences. Particular concerns included access to GPs and primary care services, assumptions and attitudes of healthcare staff, specialist and mainstream services unwilling to take responsibility or provide a service, training and skills of staff, poor quality of care, discrimination, and the use of 'do not resuscitate' notices. They recommended better training for all healthcare staff, longer and more flexible appointments, the provision of accessible information in all healthcare settings, annual health checks, ensuring accessibility to screening appointments, to identify on health records if a patient has a learning disability, that inquiries should be conducted into premature deaths, and that hospitals should fulfil their legal duty of care by providing appropriate levels of support to patients with a learning disability.

Treat Me Right concluded that:

“the NHS has a poor track record in dealing effectively with people with a learning disability. As a result, people with a learning disability have poorer health, greater health needs and shorter lives. There is a real concern that negative, discriminatory attitudes and poor communication skills amongst healthcare staff contribute to this unfortunate state of affairs...Mencap recognises that some GPs and hospitals have tried hard to improve their practices. There are examples of good practice in various areas. We want to see these shared and developed in all areas” (p31).

*2.2.3 Equal Treatment – Closing the Gap (Disability Rights Commission, 2006) and Equal Treatment – Closing the Gap: One Year On (Disability Rights Commission, 2007)*

Equal Treatment brought together three sets of data:

1. The examination of eight million primary care records and extensive consultation with service users and providers
2. Written and oral evidence analysed by a High Level Inquiry Panel



### 3. The collating of existing evidence through literature review

They found that in England and Wales, people with a learning disability and people with mental health problems are much more likely to have significant health risks and major health problems than the rest of the population. For those with a learning disability, these especially include obesity and respiratory disease. Both groups are likely to die younger than other people. The report states that “despite these stark findings, the response from primary care services and from governments has been very patchy” (p5).

The report found that people with a learning disability did not have equal access to screenings and health checks. When they were offered a health check, the checks found significant unmet health needs. When these checks were repeated a year later, further unmet needs were found, some of them major. The report also found that people with learning disabilities experience ‘diagnostic overshadowing’ where reports of ill health are assumed to be part of the learning disability and therefore not investigated or treated. It was stated that there was little or no evidence of information regarding the physical health needs of patients with a learning disability being regularly collected, collated or used by commissioners to improve services. Finally, there was extensive evidence that services were not making ‘reasonable adjustments’ (such as longer appointments, or providing accessible information), however the investigation did find some ‘impressive’ examples of positive practice. The report compiled a number of recommendations for the government, commissioners of services and primary care providers: closing the gaps of healthcare inequality should be one of the government’s major objectives, commissioners should analyse the health care needs and experiences of patients with a learning disability within their local areas and use this information to close the gaps within their services, and primary care providers should improve equality of access and treatment.

Equal Treatment: One Year On found some examples of positive action, for example, action to improve professional learning by the British Medical Association and the

General Medical Council. There were also some major weaknesses; only two out of ten strategic health authorities were found to have adequate Disability Equality Schemes, there was no further progress on provision of health checks in England, and only limited progress made in attempting to meet access needs. There has been some progress in preventing diagnostic overshadowing, with the Royal College of General Practitioners producing a Disability Equality awareness pack. The report stated that at that time there had been no action regarding screenings for people with learning disabilities. There was an over-riding concern that there has been an “absence of strategic action at the highest level” (p7), and recommendations that the Department of Health provide stronger leadership and guidance for the SHAs and the PCTs.

#### *2.2.4 Death By Indifference (Mencap, 2007)*

This report follows on from Treat me Right! It describes institutional discrimination within the NHS and how people with a learning disability are experiencing unequal and poor healthcare. These concerns are illustrated by the stories of six people with a learning disability who died whilst under NHS care - thought to have died unnecessarily through discrimination and neglect.

The report began by stating that despite the Treat me Right and Equal Treatment reports:

“There has been an astonishing lack of response to them at Government level. Health inequalities have been widely documented and solutions clearly identified – including the need for a confidential inquiry into premature deaths, annual health checks and staff training. But nothing has been done. There has been no action to prevent the disgracefully poor treatment that continues to be reported to Mencap. No action has been taken to stop other deaths like the six you will read about in this report. That is why this report has been called *Death by Indifference*” (p3).

Mencap concluded that the institutional discrimination is contributed to by:

1. People with a learning disability being seen as a low priority.
2. Many healthcare professionals not understanding much about learning disability.
3. Many healthcare professionals not properly consulting and involving the families and carers.
4. Many healthcare professionals not understanding the law around capacity and consent to treatment.
5. Health professionals relying inappropriately on their estimates of a person's quality of life.
6. The complaints system within the NHS service is often ineffectual, time-consuming and inaccessible.

These pivotal reports have each described a significant inequality in the accessibility and provision of healthcare services for people with a learning disability living within the United Kingdom. These reports have spurred interest and concern in the government and NHS, and this inequality in healthcare experience has been made a priority by both. However it appears that whilst some efforts and improvements have been made by various services and professional bodies, there may still be a distance to go before all individuals with a learning disability experience a truly equal service. It is hoped that this project investigating how patients with a learning disability cope with chronic illness will offer some insight and understanding that will be of aid to healthcare services caring for such individuals.

## 2.3 Literature Review

### 2.3.1 *Coping and Adjustment to Chronic Illness*

There are many theories and models in Health psychology that focus upon coping with illness and adjustment to illness. This part of the literature review gives an overview of a number of these, with brief consideration as to how the presence of a learning disability may affect the application of the model.

Medical professionals and researchers often refer to the terms 'adjustment' and 'coping' when thinking about illness. The Oxford Dictionary (1996) defines each term as the following:

Cope – to deal effectively or contend successfully with a person or task, to manage successfully; deal with a situation or problem (p295).

Adjust – make oneself suited to; become familiar with (p17).

These terms might then lead to the suggestion that the process of coping with a new situation, if successful, may lead to an adjustment to that situation.

Folkman, Lazarus, Dunkel-Schetter, DeLongis and Gruen (1986) define coping as:

“The person’s constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the person’s resources” (p993).

They go on to suggest that this definition has three key features: firstly that it is process oriented (it focuses upon what an individual thinks and does in response to a particular stressor), secondly that it is contextual (it is influenced by the individual’s appraisal of the demands of the stressor and the resources available to manage them), and finally that it makes no assumptions as to what constitutes good or bad coping. Coping has two major functions: regulating stressful emotions (emotion-focused coping), and altering the person-environment relation causing the distress (problem-

focused coping). Individuals vary in their preferences for a focus on the former or latter.

Sharpe and Curran (2006), define adjustment as:

“A response to a change in the environment that allows an individual to become more suitably adapted to that change” (p1154).

They go on to state that within psychology, the term ‘adjustment’ often refers to a desirable end-point (someone having ‘adjusted’ to an illness) and is often measured using indices of quality of life, life-satisfaction, self-esteem, functioning and emotional equilibrium.

The above two definitions of coping and adjustment were chosen as they were the definitions most often used and referred to in the coping and illness literature base as noted by the researcher. These definitions did not significantly shape or affect the methodology or formation of the research questions; the research questions were formed with the purpose of finding out about how individuals with a learning disability cope with renal failure, without any expectation as to what the research may uncover. There is no literature regarding how patients with a learning disability cope with chronic illness. This research area is original, and the questions were designed to be broad and encompassing in order to discover all and any ideas about coping and renal failure. The questions were not designed to test out the accuracy of current definitions of coping.

### *2.3.2 Theories of Coping and Adjustment*

The literature review now focuses upon theories that attempt to explain coping with, and adjustment to, chronic illness. Some theories have focused upon methods of coping (such as emotion-focused and problem-focused ways of coping). Other models have included cognitive theories and introduced concepts such as ‘illness representations’. More recently, two models have been proposed that attempt to

encompass the overall themes of a number of the more historical models. Below is a timeline to give an overall view of the publication of some of the most influential theories and ideas:

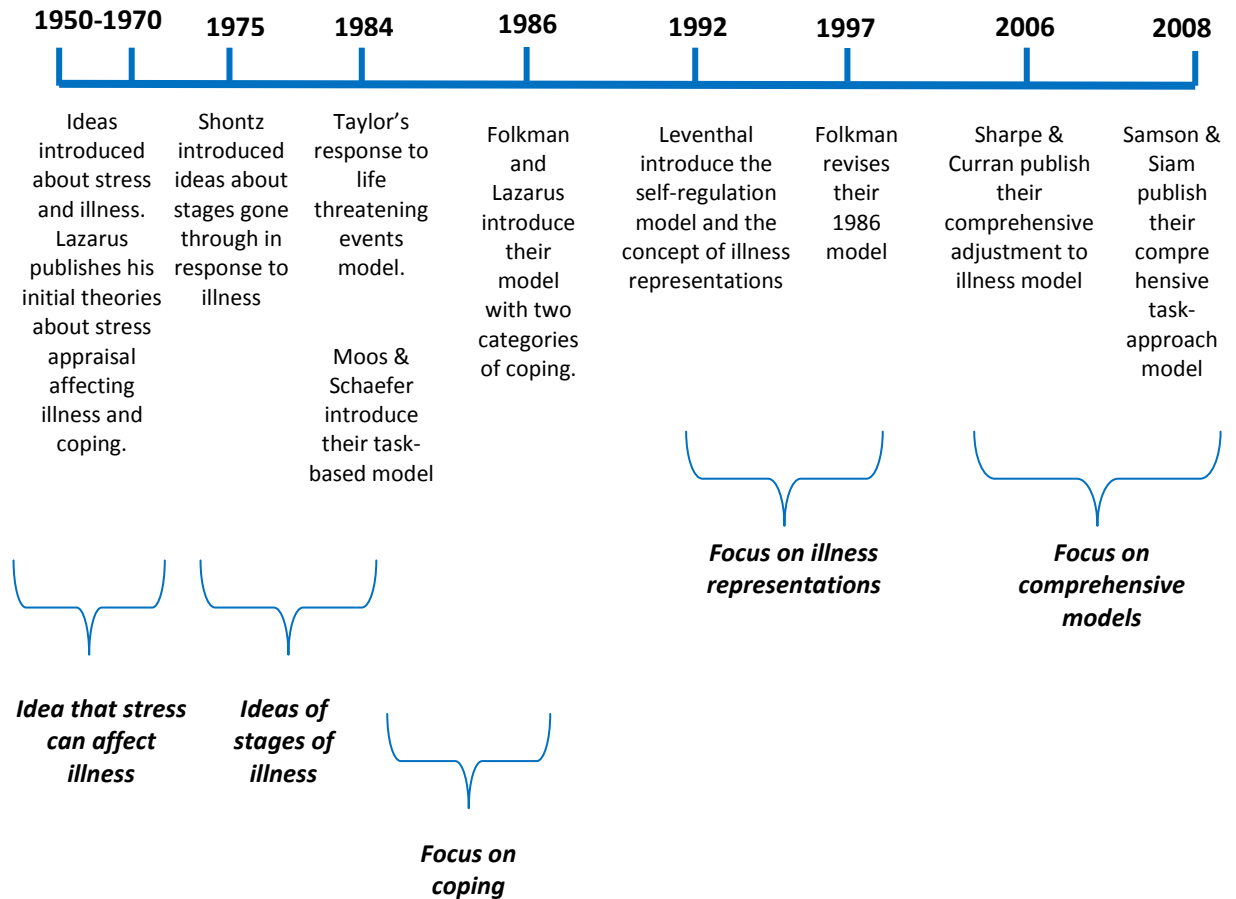


Figure 1. Timeline of Theories of Coping and Adjustment to Illness

Some of the earliest and influential ideas about coping with illness explored the concept of stress, and how the experience of stress can affect and impact upon the experience of illness. These ideas were to mark the beginning of the pioneering work of coping and illness by Lazarus. In 1966 he published his first major work ‘Psychological Stress and the Coping Process’. It was in this book that Lazarus began to shift focus away from the idea of what effects stress can have, to what effects the appraisal and management of stress can have.

Shontz was also interested in how individuals coped with illness, and more specifically he was interested in how individuals coped once given a diagnosis of serious illness. After observing a number of individuals that had been given a diagnosis, he published his work in 1975 that described the initial reactions the individuals appeared to experience after being given a diagnosis. He described their reactions within a number of stages:

- 1) Shock: characterised by being stunned, feeling detached, and behaving in an automatic way.
- 2) Encounter reaction: following the shock, individuals experience disorganised thinking and feelings of loss, grief, despair and helplessness.
- 3) Retreat: The individual may deny the illness and its consequences, and retreat into the self.

This model looks at the stages an individual may go through immediately after receiving a diagnosis. It does not, however, look at the long-term adjustment and coping processes involved with chronic illness.

As the literature review continues to consider the theories developed that attempt to explain how an individual may cope with or adjust to an illness, it would be interesting to begin to consider how these theories may be influenced or affected by the presence of a learning disability. As the review progresses and considers how the models may be affected by a learning disability, it is aimed that these considerations are treated as wonderings and ideas only, not as assumptions or predictions. For example, for Shontz's model, it may be that the presence of a learning disability would not affect the individual's journey through each stage of this model; having a learning disability does not mean that an individual cannot experience shock, grief and denial. A learning disability may make it more difficult for an individual to be able to manage and understand their emotions and emotional responses. It may be that if an individual is unable to understand what is happening, they may move straight to denying it. For example, Evenhuis (1997) found that people with a learning disability tended to

tolerate symptoms or express them atypically as irritability, inactivity, loss of appetite and sleep problems. This may illustrate that if an individual with a learning disability is experiencing illness, instead of understanding that what they are experiencing are symptoms of physical ill health and expressing them as so, they may react in a way similar to denial; by tolerating how they are feeling or expressing how they are feeling atypically by showing irritability or not sleeping well.

For individuals with a learning disability, there may be a number of barriers to their understanding of illness. Firstly, there is the severity of the learning disability. Emerson, Hatton, Bromley and Caine (1998) found that adults with a mild learning disability were able to locate pain in the same way as controls using a body map and photographs. However, the more severe the learning disability, the more unlikely it is that the individual has the cognitive capacity to understand what is happening in their body, to locate pain within their body, and to have the communication skills to express this.

Communication ability can be another barrier to understanding. Impairment of speech and language is commonly associated with learning disability (McQueen et al, 1987). Speech and language development can be delayed or abnormal, or speech can be completely absent (Carr, 2007). Carr goes on to describe that individuals with a mild to moderate learning disability often experience delays in the emergence of speech and aspects of language use, whilst nearly all individuals with a severe or profound learning disability have a severe language impairment (where speech is completely absent, or does not meet the required communicative needs of the individual). Lennox, Diggins and Ugoni (1997) found that communication and difficulties with history taking were the most prominent responses from primary care physicians when asked about barriers to care. Medical terminology consists of many long and complicated words and concepts that individuals with a learning disability may find difficult to understand.



In 1983 Taylor proposed a theory of adaptation to threatening events, such as chronic illness, which involves the individual moving through a number of stages and processes that begin following the event. However unlike Shontz's stages, her three processes are strongly rooted in ideas that involve *cognitive* adjustment. She interviewed cancer patients, cardiac patients and victims of sexual assault and theorised that individuals adjust to the experience of a threatening life event by going through these three processes:

- 1) A search for meaning: a search for why a crisis has occurred and the understanding of its impact and the implications. It involves trying to answer questions like 'why has this happened? What about my life now?'
- 2) A search for mastery: a sense of mastery can be achieved by developing a belief of having, and achieving some control over the illness. It involves answering questions like 'what can I do to manage it? How can I prevent a further difficulty/illness occurring?'
- 3) A process of self-enhancement: individuals may suffer a decrease in self-esteem through illness that they attempt to re-build.

How might the presence of a learning disability affect Taylor's model? A learning disability may affect an individual's ability to search for the meaning (to seek out, hold, and sort through information to answer the causality and implications of the illness; a learning disability means that an individual is less able to learn and sort through complicated information. The more severe the learning disability the more difficult understanding, holding and sorting through information is). Patients with a learning disability may not have the means or ability to undertake and control some aspects of their illness (for example, many individuals with more severe learning disability may also have sensory or physical disabilities, or may have difficulty in being able to predict future difficulties, both of which may affect their 'mastery' of the illness). Wehmeyer and Palmer (2003) describes that individuals with a learning disability are more likely to have an *external* locus of control. They are more likely to attribute causes and control of events as being external (rather than internal) and thus more out of their

control. Individuals with a learning disability may also experience a decrease in their self-esteem. A further consideration is whether they have the same access to strategies and the same ability to be successful at self-enhancement. Maintaining self-esteem is an important skill. Carr (2007) writes how the development of this skill follows a distinct trajectory in individuals with a learning disability. Adolescents with a learning disability develop less differentiated self-concepts (compared to adolescents without a learning disability). They make little distinction between self-evaluations of themselves in the social, cognitive and physical domains (p73).

The next model of coping to be published and have significant influence in the field of health psychology was that of Folkman and Lazarus et al in 1986. Shontz and Taylor had previously thought about reactions to illness, and introduced the idea of moving through stages and adjusting cognitively. They did not, however, include ideas around coping and what strategies might be utilised. Folkman and Lazarus' model focuses more upon how individuals actually cope with an illness. Like Taylor, they believe individuals have a cognitive reaction to illness, but they then introduce the two major categories of coping (emotion focused and problem focused coping) in response to the cognitive reaction. The theory identifies two processes: cognitive appraisal and coping. Cognitive appraisal involves the evaluation of and the extent to which an interaction between a person and their environment is stressful. Folkman and Lazarus argue that the interpretation and perception of how stressful an event is, is more important than the event itself. Firstly, a primary appraisal is made. This is a cognitive appraisal of the effect of a situation on our well-being. The effect may be interpreted as irrelevant, positive or stressful. A secondary appraisal is then made of how best we can deal with this situation, by asking questions such as 'what options are available to me?' and 'how likely is it that it will alleviate my distress?' Finally, a reappraisal is made that takes into account any changing information.

Coping is the process in which the individual tries to manage the demands of this interaction between the person and their environment. Coping strategies fall under two broad categories of coping; emotion-focused and problem-focused. Problem-

focused coping involves utilising strategies that attempt to deal with the problem or situation itself (such as looking for information, taking medication, and talking to others). Emotion-focused coping focuses upon dealing with the emotions raised by the situation rather than with the situation itself (for example, using denial or wishful-thinking in order to protect the self from feelings of worry or anxiety). Individuals can differ in how they prefer and utilise each form.

A learning disability may affect how an individual cognitively appraises the stress of the illness and the interactions between himself/herself and the involved environments (such as the hospital and dialysis). A learning disability may affect the options the individual may have to deal with the situation and how they then cope with the demands of the illness, its treatments and the resulting emotions and change in emotional states. Carr (2007) writes about how cognitive constraints can make it difficult for individuals with a learning disability to recognise emotions in themselves and others because emotions are complex stimuli to process (p73). He goes on to describe how the cognitive constraints inherent within learning disability make it difficult for people with a learning disability to regulate their own emotional state (and use techniques such as distraction), and they find it more difficult to respond in a socially skilled way in situations where someone else is displaying heightened emotion (p73). Carr goes on to say that:

“Over the long term, difficulties in recognising, regulating and responding to emotions in others and following social rules render the process of making and maintaining long-term relationships more difficult for people with intellectual disabilities” (p73).

This difficulty in maintaining long-term relationships may mean that patients with a learning disability perhaps have fewer long-term relationships in which to find comfort and support when ill.

In 1997, Folkman reviewed and adapted the cognitive appraisal and coping model by including the concept and roles of positive psychological states, in the Adjustment to

Illness Model which includes a third type of coping category – ‘meaning-based coping’.

Folkman looked at coping within individuals diagnosed with HIV and their carers. She found four types of coping that were associated with positive psychological states: positive reappraisal, goal-directed problem-focused solving, spiritual beliefs/practices, and infusing ordinary events with positive meaning. She hypothesised that these four processes of coping had a common underlying theme of searching for and finding positive meaning. These four processes of meaning-based coping may be utilised if initial coping strategies (problem-focused and emotion-focused strategies) lead to no resolution or an unfavourable resolution, and perhaps to distress. If utilised, the meaning-based coping strategies can then lead to positive emotion and can sustain the coping process.

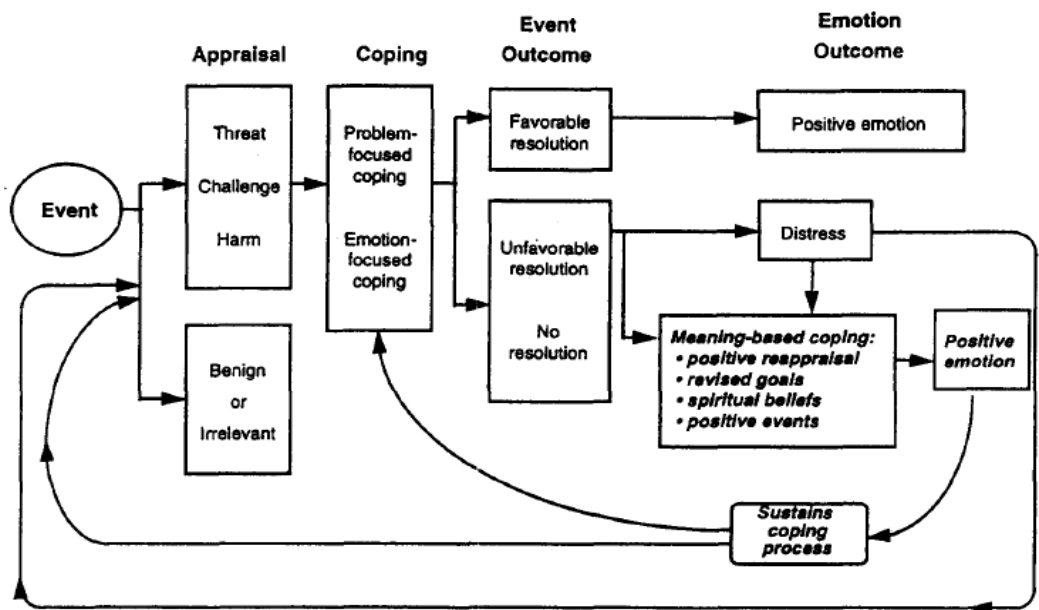


Figure 2. Revised Cognitive Appraisal and Coping Model. Adapted from Folkman 1997, p1217.

The presence of a learning disability may mean that the individual is unable to cognitively positively reappraise and revise goals due to cognitive constraints. It may be that the carers and family of the individual will need to do this for them.

Running almost parallel to the publication of Folkman and Lazarus's original model, was the publication of Moos and Schaefer's influential Model of the Coping Process in 1984. Moos and Schaefer theorised a task-based model that they believe individuals go through in order to cope with chronic illness. Similar to Folkman and Lazarus, the model involves utilising coping strategies. However, these strategies are utilised not in response to a cognitive appraisal, but in order to fulfil two main coping tasks:

- Tasks relating to the illness or treatment: these involve learning to cope with the symptoms or disability caused by the illness, adjusting to the hospital environment and medical procedures.
- Tasks related to general psychological functioning: these involve trying to control negative feelings and keeping a positive outlook, maintaining a satisfactory self-image and sense of competence, preserving good relationships with family and friends, and preparing for an uncertain future.

They suggested a number of coping strategies that individuals might employ in trying to work through the above tasks in the coping process:

- **Denying or Minimising** the seriousness of the situation. This can be beneficial in the early stages of adjusting to an illness by using it selectively to put aside emotions temporarily so they do not feel overwhelmed and allows time to organise other coping resources.
- **Seeking Information** about the illness and treatments.
- **Learning to Provide One's own Medical Care** - patients may gain a sense of control and personal effectiveness.
- **Setting Concrete, Limited Goals** such as exercising, going to social occasions and maintaining routines. Patients and families then have something to look forward to and something meaningful to achieve.
- **Recruiting Instrumental and Emotional Support** from family, friends and medical staff.
- **Considering Possible Future Events** and stressful events in order to know what may happen and to prepare for the unexpected.
- **Gaining a Manageable Perspective** on the illness and its treatment by finding a long-term 'purpose' and 'meaning' for the experience.

**Table 1. Coping Strategies, Moos & Schaefer (1984)**

Individuals with a learning disability may not have the resources to seek out and then understand information about the illness and its treatments. One effect of this may be that being unable to understand the illness may have a similar effect of minimising or denying the seriousness of the illness. It may also mean that the individual is left feeling uncertain and unsure about what is happening, unable to use information as a cognitive control of anxiety. As discussed above, individuals with a learning disability may find it difficult to identify and regulate their emotions. The cognitive constraints may mean that they will be unable to understand and use medical information to calm such emotions that feel uncontrollable and difficult to comprehend. Patients with a learning disability may not have the cognitive capacity or physical ability to be able to provide their own medical care, and as such are unable to gain a sense of control from utilising such a strategy. They may also be unable to consider possible future events and plan for them. However, the strategies of setting and achieving concrete goals, and recruiting emotional support should be more accessible.

The models discussed so far have focused more upon ideas around coping strategies and tasks. Leventhal, Diefenbach and Leventhal introduced their dual-processing model in 1992. This model is known as the *Self-Regulation Model* or the 'Common-Sense Model' and it also became influential within the health psychology field. Their model introduces the idea of the individual forming '*illness representations*'. The concept of 'illness representations' has since been used in other theories of coping and adjustment to illness, and has inspired research and studies that look at what effects illness representations can have upon outcomes of illness.

The self-regulation model can be conceptualised as below:

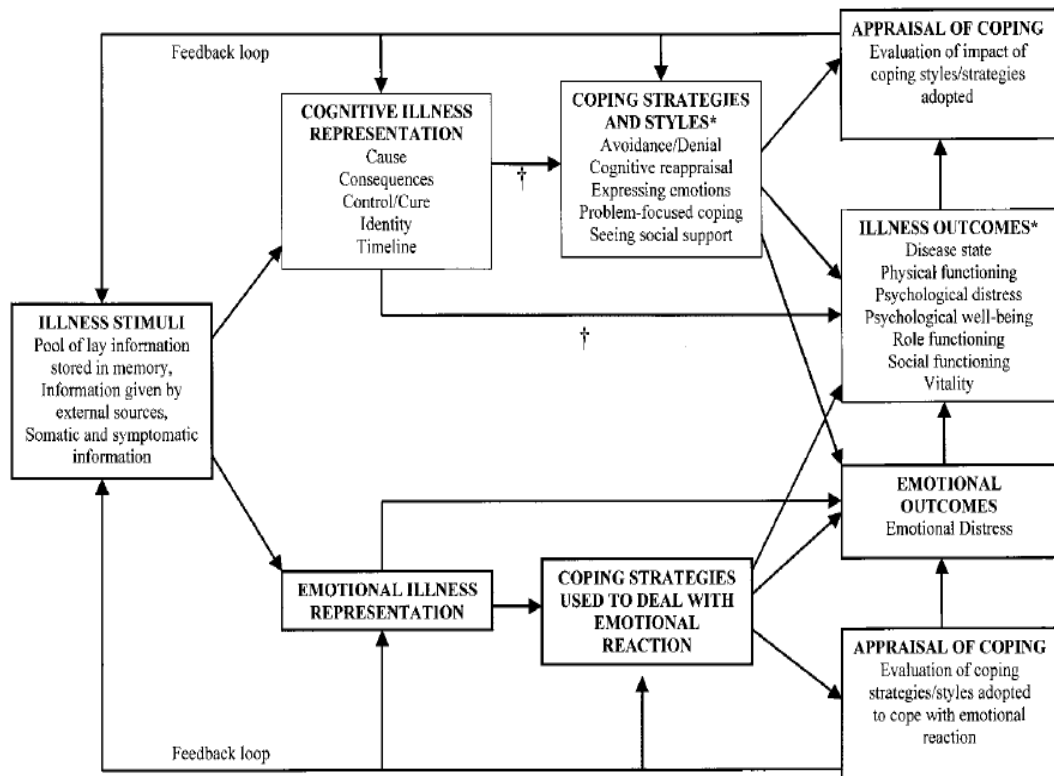


Figure 3. The Self-Regulation Model. Adapted from Hager & Orbell 2003, p144.

The self-regulation model can be broken down into three basic stages (Ogden, 2004. p53):

- 1) Interpretation: making sense of the problem. This leads to the production of 'illness representations'. The interpretation of symptoms ('I am in pain') and social messages about the illness ('the doctor says I have...') leads to the individual attempting to find meaning in the illness by forming a cognitive illness representation (which is a cognitive construct of the identity and cause of the illness, its consequences, the timeline and the level of control over it). The news and identification of an illness also leads to a change in emotional state, and the formation of an emotional illness representation (for example, fear, anxiety or depression).

- 2) Coping: dealing with the problem in order to regain a state of equilibrium. The cognitive and emotional illness representations allow the individual to develop and consider coping strategies that must relate to both the representations. Attempts at coping can involve a number of strategies that are problem-focused or emotion-focused.
- 3) Appraisal: evaluating the effectiveness of the coping strategy and deciding whether to continue with the strategy or to try a different one.

The self-regulation model has been used to relate illness perceptions to behaviours, such as patient compliance and adherence to treatment regimes, and to relate illness perceptions to emotional outcomes (for example, patients with a strong illness identity, passive coping styles and views that the illness is serious and long-term have poorer outcomes, Sharpe & Curran 2006).

When considering the self-regulation model for individuals with a learning disability, it is likely the presence of a learning disability will affect the interpretation of the illness and the formation of the representations. The difference in cognitive ability may affect the formation of cognitive representations, and perhaps difficulties in understanding and managing emotions will affect the formation of emotional representations. According to the model, these representations may then lead differently to the availability and consideration of a set of coping strategies (so they may be the same strategies, but the access, availability and consideration of them may be diminished).

More recently, two models of coping and adjustment have been produced that attempt to incorporate the themes seen within the previously reviewed models. These models have been proposed by Sharpe and Curran (2006), and Samson and Siam (2008). Sharpe and Curran's model is more cognitive in nature with a strong emphasis on illness representations, whilst Samson and Siam's model is task-based in nature.



Sharpe and Curran (2006) reviewed a number of models that predict health beliefs and that look at the adjustment to chronic illness. They attempted to incorporate the commonalities between the reviewed models and proposed their own overall Model of Adjustment to Chronic Illness. When faced with illness, individuals develop illness representations (that are influenced by pre-existing beliefs). The adjustment to the illness is the process of trying to maintain a positive view of the self and the world despite the illness. For example, for those with good prognosis and high levels of optimism, the development of helpful representations from the outset is likely. As long as these representations match the reality, positive psychological adjustment and functioning is probable. These optimistic and accurate views may lead the individual to make positive and helpful choices in terms of coping strategies and management. Conversely, sometimes due to severity of the illness or its consequences, previous beliefs or experiences, or personal characteristics, representations can be formed that are not helpful. These individuals must then find other ways in which to incorporate their representations into their views of themselves and the world. The model is demonstrated below:

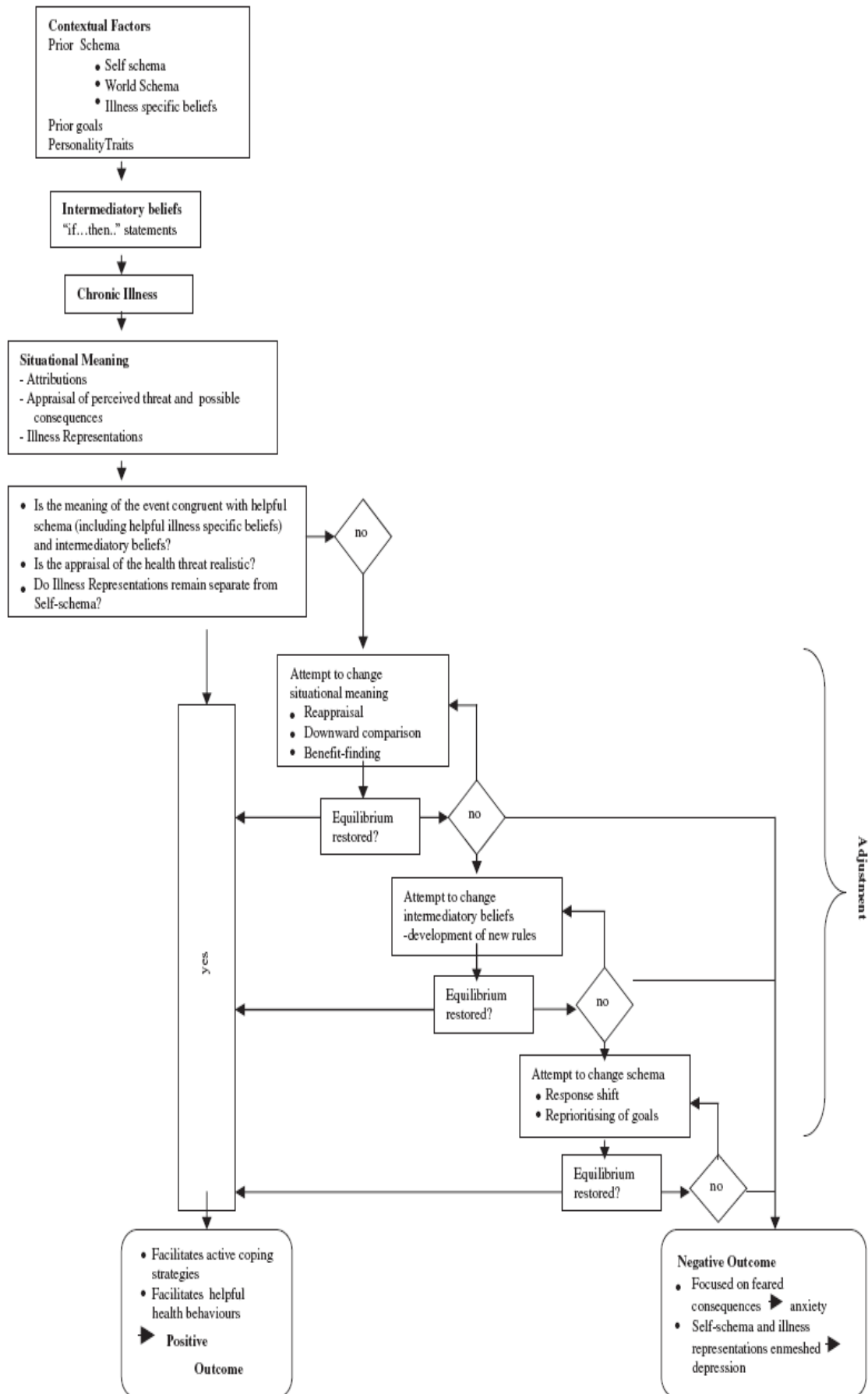


Figure 4. Model of Adjustment to Illness. Adapted from Sharpe & Curran 2006, p1162.

This model focuses heavily upon cognitive ideas such as previous beliefs and schemas, current schemas and the production of illness representations. The presence of a learning disability may affect all of the above. This may not always be a disadvantage; for example, if the prognosis of the illness is poor it may be that a vague focus is more consistent with positive behaviour and outlook.

Samson and Siam (2008) reviewed a number of task-based models that attempt explanation of adaptation to chronic illness (such as Moos & Schaefer 1984), and similarly to Sharpe and Curran incorporated the themes that they believe are common to all the models and proposed their own overall Comprehensive Task-Model Approach:

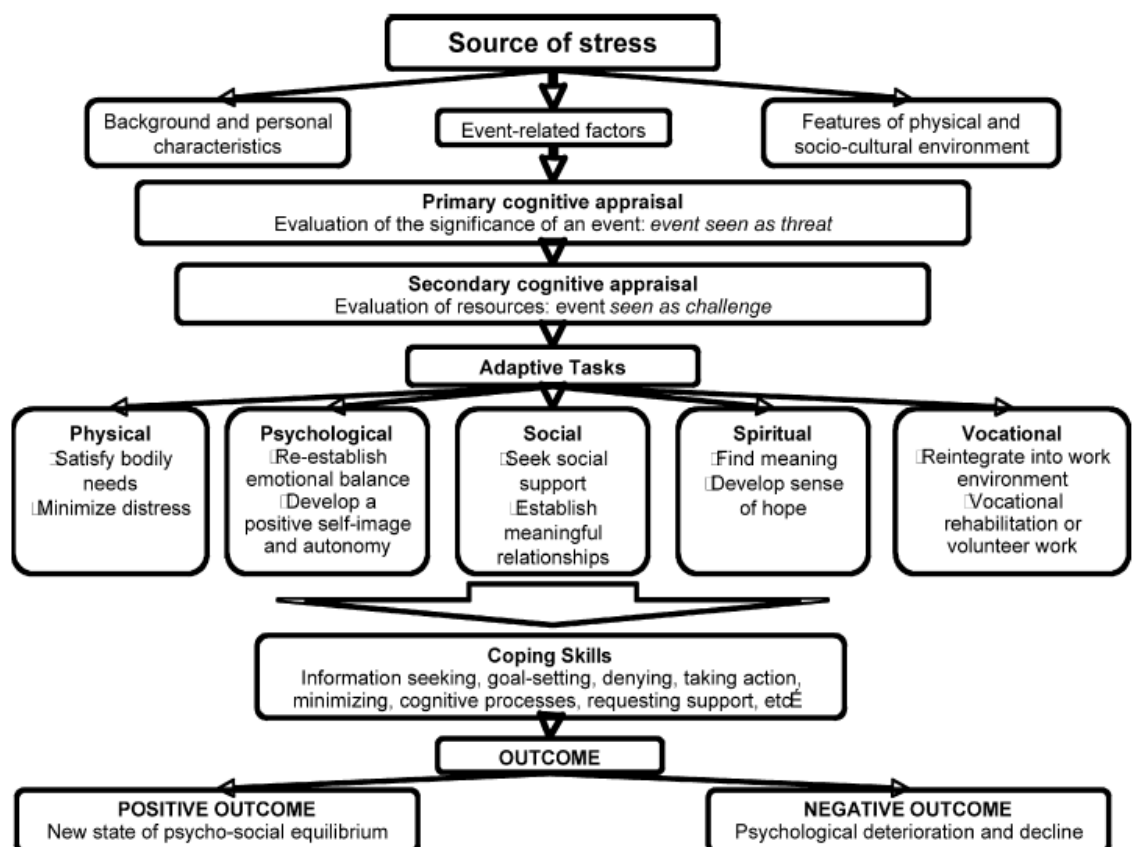


Figure 5. The Comprehensive Task-Model Approach. Adapted from Samson & Siam 2008, p428.

This model emphasises the role of stress and cognitive appraisal influencing behaviour (which is similar in concept to that of Lazarus & Folkman's model of cognitive appraisal

and coping). The individual's response is described as physical, psychological, social, spiritual and vocational adaptive tasks. Individuals with a learning disability may experience difficulties in carrying out all of them. There may be difficulties in looking after themselves physically, difficulties in re-establishing emotional balance, and dependency upon others to seek out support.

This section of the literature review has followed the initial timeline of psychological research. These responses have initially looked at the responses and processes seen in individuals diagnosed with an illness or who have experienced a life-threatening event. They have then focused upon strategies of coping and subsequently upon cognitive and emotional illness representations. Finally, the more recent models of adjustment have attempted to incorporate the commonalities and themes seen in the more historic models. What has become apparent through this part of the literature review is the potential for disparity that the presence of a learning disability may have upon these models and the ideas and processes they attempt to describe.

This study has not been underpinned by any of the models or theories of coping reviewed above. The purpose of the review was to prompt interest and questioning into this new area of research (for both the researcher and reader); such as wondering how might learning disability affect coping with illness? How might it change or alter this model? How would learning disability fit here in this theory? The literature review and the queries it raised is seen as an introduction to and a beginning of the process of attempting to answer a question never previously asked: 'how might an individual with a learning disability cope with being ill?'

### *2.3.3 Coping, Age and Gender*

There are a number of studies that have investigated coping styles in relation to age and gender. For example Lynch, Kashikar-Zuk, Goldschneider and Jones (2007) investigated sex and age differences in coping styles among children with pain. They

found significant sex differences in coping strategies utilised; girls sought more social support, whilst boys used more behavioural distraction techniques. Some coping differences in age were also found; for example, adolescents engaged in more positive self-statements (a cognitive strategy) than children did. However, no differences between sex, age and coping efficacy were found. They hypothesised that sex and age based preferences in coping style may begin to develop in childhood. Felton and Revenson (1987) focused upon age differences in coping with chronic illness. They studied the coping strategies of 151 middle-aged and older age chronically ill adults and found that older adults were less likely to use emotional expression and information seeking in comparison to the middle-aged adults. The older adults were also more likely to cope by minimising the illness' threat. Matud (2004) focused on investigating gender differences in stress and coping styles. He looked at stress and coping in 2816 people (1566 women and 1250 men) aged between 18 and 65 years old. They found that women scored significantly higher than the men in chronic stress and minor daily stresses. Women were more likely to use emotional and avoidance coping styles, whilst men were more likely to employ rational and detachment styles of coping. Matud summarises that his study suggests women suffer more stress than men, and are more likely to employ emotion-focused styles of coping. However, it should be noted that the effect sizes for this study are low.

Unfortunately it is beyond the scope of this literature review to discuss this area in more depth, especially in relation to learning disability. There is little to no research regarding learning disability and coping, and no research regarding gender and age in learning disability and coping. The numbers of patients with a learning disability known and discussed by the participants in this study was small; comparisons regarding differences in coping by age and gender were not made. The focus about coping remained fully upon the affect and impact of learning disability and renal failure.

### *2.3.4 Coping with Dialysis*

Dialysis requires large changes in day-to-day life and major adjustment. This section of the review first looks at the work of Kimmel, who has written about the general effects and demands of dialysis, and the prevalence of depression in dialysis patients. The review then focuses upon a series of studies that have investigated the quality of life of individuals who have dialysis. The review then concludes by looking at a study that describes how a number of individuals cope with dialysis.

#### 2.3.4.1 Demands of Dialysis

Kimmel has carried out a number of studies looking at patients receiving dialysis. In 2001 he suggested that the possible stressors in the life of a patient on dialysis are numerous and can include:

“ dietary and time constraints, functional limitations, loss of employment, changes in self-perception, alterations in sexual function, general and perceived effects of illness, medications used to treat the illness, and fear of death” (p1600).

He wrote that treatment with haemodialysis can result in the following demands:

“potential changes in a patient’s status in marital, occupational, and societal contexts; the expenses and worries associated with the treatment and the illness, and the uncertainty, anxiety and costs entailed while waiting for a transplant...Disability and marital and family dysfunction can occur, as well as depression, anxiety, loss of one’s role and identity, and development or worsening of alcohol and substance abuse” (p1600).

Kimmel writes of several major factors that can affect the lives of haemodialysis patients (p1600): depression, perception of the burden of illness, social support, and marital, familial, therapeutic, residential and socioeconomic circumstances.

Thong et al (2007) carried out a study with 528 patients looking at the support needed for patients receiving dialysis. The patients filled out the Social Support List three months after beginning dialysis. They found that the presence of a discrepancy between expected and received support (of social companionship, daily emotional support and total support) was associated with increased mortality, and they emphasised the importance of support for patients on dialysis. It should be noted that the Social Support List was only administered once which was three months after the beginning of dialysis, where it is possible that the individual will be going through a significant adjustment to the dialysis, consequently needing a lot more support (than perhaps they may need, for example, a year later). The study may have gained more insight from more frequent completion of the measure over the course of the illness.

#### 2.3.4.2 Dialysis and Depression

A number of studies have looked into whether depression is more prevalent in patients with chronic kidney disease. In 2006 Kimmel and Peterson reviewed a large number of these studies and looked at the prevalence of major depression or a defined psychiatric illness within patients with chronic renal failure. They reported that the exact figures are not known, but that it is likely to be between 5-10%. They go on to report that the prevalence of increased symptoms of depression (although not major depression) are far greater, and that there is in fact an association between depressive affect and morbidity, quality of life, and mortality in chronic renal failure populations.

#### 2.3.4.3 The Effects of Dialysis upon Quality of Life

Research has been carried out looking into the experiences of dialysis and effects upon quality of life. Maiorca, Ruggieri, Vaccaro and Pellini (1998) carried out a quantitative study where 166 patients completed a quality of life questionnaire, and found that the type of dialysis undertaken affected the psychological well-being of the patients. More

specifically, they found haemodialysis patients felt more reassured as their treatment was carried out in hospital, but struggled with feeling less autonomous and more dependent upon the hospital and staff. Patients having peritoneal dialysis felt more autonomous and independent, but experienced more feelings of anxiety and insecurity. Finally, they found that all patients expressed feelings of conditioning and a sense of social exclusion (reporting that the illness had disrupted their lives and was affecting their work life, relationships with others and leisure activities).

Krespi, Bone, Ahmad, Worthington and Salmon (2004) looked at the beliefs held by haemodialysis patients about their chronic kidney disease and dialysis. Many viewed dialysis as an inconvenience that inhibits but that is necessary. Some felt that life revolved around dialysis. For some, haemodialysis was also frightening. Haemodialysis was viewed by some to have positive effects such as causing the individual to feel lighter or breathe easier. Some expressed improvements in physical appearance. However, others believed that haemodialysis weakened their body, leaving them feeling tired, weak, and vulnerable to infection. It was also blamed for pain, lack of sleep and stiffness (p193).

Hagren, Petterson, Severinsson, Lutzen and Clyne carried out the first of two qualitative studies in 2001 (the second was in 2005), looking at the experiences of patients with chronic renal failure on haemodialysis. They found a major theme of 'dependence' upon the haemodialysis machine, and that this dependence was felt to be time-consuming and tiring, affecting marital, family and social life. Better adjustment was seen in patients who expressed acceptance of dependence on dialysis and who maintained autonomy by being seen as an individual by carers. In 2005, Hagren et al looked more specifically at how patients with chronic renal failure who were having haemodialysis experienced their 'life situation'. They identified three major themes, with four sub-themes (p294):

- 'Not finding space for living' – consisted of 'struggling with time-consuming care' and 'feeling that life is restricted'.



- 'Feelings evoked in the care situation' – consisted of 'sense of emotional distance' and 'feeling vulnerable'.
- 'Attempting to manage restricted life'.

Santos et al (2009) reviewed the literature and carried out a two-year follow-up study of patients having haemodialysis and reported that due to life restrictions and dialysis being unable to fully substitute renal function, quality of life scores for patients who have haemodialysis are very low. However, despite finding a substantial decline in quality of life, they found some improvements over time for the subscales pertaining to the mental component (social functioning, role, mental health), and that psychological adaptation programmes for patients were of benefit.

#### 2.3.4.4 Coping with Dialysis

Mok, Lai and Zhang carried out further qualitative research in 2004. They carried out a study looking at how eleven patients in Hong Kong coped with chronic renal failure.

They discovered the major themes for the participants were those of:

- coping with fluctuating feelings (such as helplessness, powerlessness, sadness, guilt, fear, anger, indebtedness),
- concerns and demands (role reversals with spouses and relatives taking on their responsibilities, managing financial difficulties, alterations in body image),
- motivation to cope (family as a motivator to continue living and fulfilling responsibility),
- coping strategies (avoidance, acceptance of the illness, spiritual support, and use of cognitive strategies such as living each day as it comes, having a positive attitude, making comparisons, using distraction, and re-evaluating life perspectives).

It should be noted that this study is quite small and that it takes place in Hong Kong. Although hospital and treatment experiences may be similar, values and culture in Hong Kong may be different in comparison to the United Kingdom. However, the study does look specifically at coping with renal failure and provides some useful insight into how individuals without a learning disability cope with this illness.

Yeh, Huang and Chow (2008) carried out a much larger quantitative study looking at coping within 2642 haemodialysis patients. They found that patients with comorbidities experienced higher levels of stress, but that interestingly the comorbidity perhaps acted as a moderator in the relationship between coping and stress as these patients with comorbidities were more likely to employ positive coping strategies.

### *2.3.5 Coping with Chronic Illness with a Learning Disability*

There are few studies that report the experiences of patients with a learning disability within a healthcare setting, and even fewer that look at the experiences of chronic illness and its treatment. This part of the review discusses the limited research found, namely research in measuring pain and distress in patients with a learning disability, a recent research project (the 'Veronica Project') that is exploring the experiences of patients with a learning disability and cancer, and some studies that describe adaptation of information resources developed by individual services to aid understanding of dialysis for patients with a learning disability. It concludes by examining a model proposed by Wehmeyer and Garner (2003) that describes how an individual's environment can contribute to and encourage self-determination.

Many individuals with a chronic illness may also experience pain and chronic pain. Being able to identify and understand expressions of distress and pain in people who are unable to communicate is important, first, so that pain can be identified and treated, and second because misinterpretations can easily be made; a reduction in

activity can often be misinterpreted as contentment (instead of distress), and an increase in activity due to distress can be misinterpreted as 'challenging behaviour'. Regnard et al (2007) developed the Disability Distress Assessment Tool (DisDAT), a tool that aids carers in sharing and advocating information about how their loved ones who have profound learning disabilities communicate distress. The tool was assessed using both qualitative and quantitative methods with 56 carers and 25 patients who had severe communication difficulties. They summarised that:

"The DisDAT empowers carers to have more confidence in their observations of distress, and provides a means of identifying the cause and then monitoring the effects of treatment" (p285).

Lewis, Bell and Gillanders (2007) also focused on chronic pain in patients with a learning disability. She looked at what strategies help people *without* a learning disability cope with chronic pain and adapted this for a client with a learning disability who suffered from chronic pain with positive results. Lewis developed a cognitive-behavioural pain management intervention by adapting and making accessible a manual for non-disabled adults (the exact adaptation of this manual was not made clear). This aimed to help meet the physical, social and cognitive needs of the client in question (p93). Sessions occurred once a week for four months. Throughout the therapy improvements were reported by reduction in pain intensity, and in reduction of levels of anxiety and depression. These reductions were measured by completion of a depression and anxiety scale, and two pain specific scales. These scales were administered at baseline, month 2 and month 4 of treatment. This study is important as it indicates how the adaptation of techniques typically used in individuals without a learning disability can perhaps be helpful in lowering the pain and distress in someone who does, and consequently that more research and further development of therapeutic techniques is needed.

In 2008, the British Journal of Learning Disabilities published a special issue that looked at patients with a learning disability who had been diagnosed with cancer. Within this issue McEnhill (2008) carried out a small-scale audit with patients with a learning

disability who had been diagnosed with cancer around their experiences of how the diagnosis was discussed with them (it is known that how well 'bad news' is broken to a patient is very important, having effects upon relationships with staff and services, and psychological adjustment to the diagnosis). It was found that doctors often did not communicate directly with the patient about their illness, and that current 'breaking bad news' training models do not take into account the needs of patients with a learning disability. This audit was very small so results cannot be generalised, but the study indicates future consideration of this important topic within the chronic illness experience.

Tuffrey-Wijne (2008), published the first qualitative interview (of what is planned to be twenty) of 'John Davies' story and experience (in his own words) of having a learning disability and being diagnosed and receiving treatment for cancer. His story is part of the ongoing 'Veronica Project' which is interviewing twenty patients with a learning disability with cancer and analysing the data with grounded theory to produce a theory of how patients with a learning disability experience cancer and how best cancer and palliative services can support them. The project aims to look at the experiences of hearing the diagnosis, through treatment options and experience of treatment, and finally through to end of life and palliative care (if the condition is terminal). This project, overall, has a similar purpose and design to this study, although there will be differences between the illnesses (such as length and outcome of illness, and length and invasiveness of treatments) that will likely affect the coping and adjustment to them.

The literature search found no studies that looked at how patients with a learning disability experience renal failure and dialysis as a form of treatment, although there are a small number of studies that describe how individual services have adapted resources or developed accessible materials to help patients with a learning disability understand renal failure and dialysis (Neville, Jenkins, Williams & Craig 2005, and Jenkins, Jones & Griffiths 2008).

The literature search found no models that look at coping and adjustment to illness for individuals with a learning disability, however Wehmeyer and Garner (2003) proposed a model depicting how a person's environment can play an important role in promoting self-determination in individuals with a learning disability. Self-determination may be an important factor when considering how someone may cope with a chronic illness. They state that there are two major contributors to level of self-determination (p255):

- 1) The capacity of the person to act in a self-determined manner (the person's ability to make decisions, set goals and solve problems, whether the individual can advocate for themselves, and whether links can be made between performing a behaviour and the outcome).
- 2) The degree to which an individual's environments that they live, learn, work and play in provide opportunities for them to exert control in their lives and to make choices.

The model predicts that both environmental and personal characteristics contribute to enhanced self-determination:

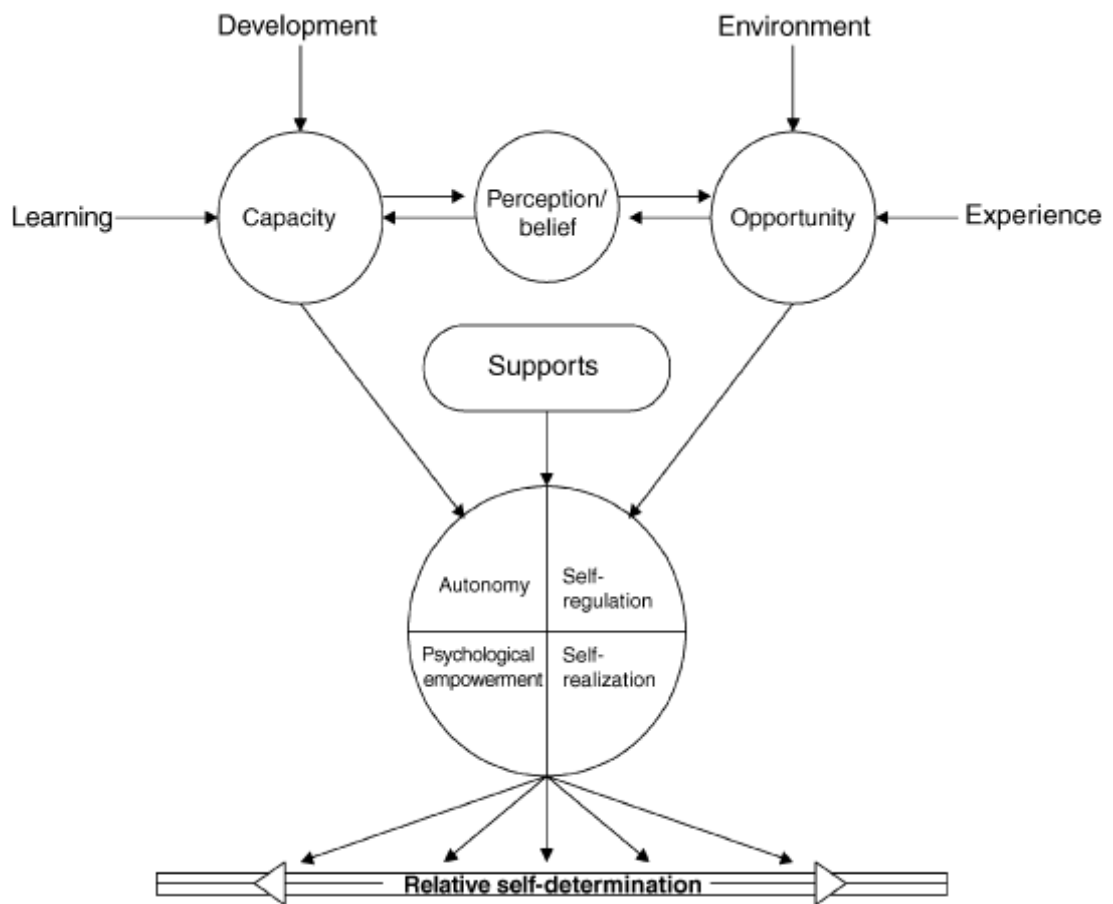


Figure 6. A Functional Model of Self-Determination. Adapted from Wehmeyer & Garner 2003, p256.

Wehmeyer and Garner argue that:

“if we look beyond ‘intelligence levels’ and leave behind stereotypes and biases held about people with intellectual disability, we can, in fact, enhance and promote self-determination and, in turn, further promote a higher quality of life for people with intellectual and developmental disability” (p264).

This may mean that the environment (for example, of hospital and home) may have an impact upon how self-determined individuals with a learning disability and a chronic illness are.

## 2.4 Summary of the Reviews

The following points have become evident from the review of the literature:

- Healthcare for patients with a learning disability is an important topic, one prioritised by the government, NHS, charities and the Health Care Commission.
- Healthcare for patients with a chronic illness is an important topic, prioritised by the Department of Health.
- Chronic kidney failure is an important example of a chronic disease. It involves the making of a number of difficult decisions and adherence to complicated and difficult treatment regimes. The major form of treatment for chronic kidney disease, dialysis, requires large adjustments to be made by the individual, increases the likelihood that the individual may experience symptoms of depression, and can have significant detrimental effects upon quality of life.
- There is little research that looks at chronic illness and learning disability.
- The previous and current psychological models of coping with and adjustment to chronic illness do not take into consideration the possible effects of having a learning disability, and are likely to be influenced and changed by the presence of a learning disability.

It is evident that investigating how individuals with a learning disability cope with chronic kidney disease is an important research topic, and one that is likely to provide valuable insight and enhance understanding of the issues raised above.

## **3.0 Research Aims and Questions**

### **3.1 Research Aims**

The main aims of the research were:

- To add insight and understanding to a small research base about how people with a learning disability may cope with a chronic illness and its treatment.
- To use grounded analysis to produce two models of how people with a learning disability may cope with chronic kidney disease. These models will have emerged from consultant and family/carer data.

A further result of the research may include:

- The research may highlight good practice within the renal service with relevance for other services. It may also produce further considerations for the service such as indications for further training.

### **3.2 Research Questions**

The research questions that helped guide the study were:

1. How do consultants perceive patients with a learning disability cope with stage V kidney disease and its treatments? This will focus on how patients with a learning disability cope with various aspects of the condition and treatment and will cover the following:

- What are their perceptions about how patients cope with symptoms of the illness?



- What are their perceptions about how patients cope with decision-making?
- What are their perceptions/processes about assessing whether a patient can cope with a treatment?
- What are their perceptions about how patients cope with the treatments, in particular dialysis and transplant?
- What are their perceptions of how well consultants cope treating patients with a learning disability?
- What are their perceptions of the quality of service provided for patients with a learning disability?

2. How do families and carers perceive their family member has coped with stage V kidney disease and its treatments? This will focus on how patients with a learning disability cope with various aspects of the condition and treatment and will cover the following:

- How do the families/carers perceive the individual coped with the onset and diagnosis of the illness?
- How do the families/carers perceive the individual coped with decision-making about their condition?
- How do the families/carers perceive that the individual copes with symptoms of their illness?
- How do the families/carers perceive that the individual copes with the treatments, in particular dialysis and transplant?

## 4.0 Method

### 4.1 Summary of Design

This project has adopted a qualitative approach to explore how patients with a learning disability cope with chronic renal failure. Patients with a learning disability diagnosed with a chronic illness, such as renal failure, are low in number in comparison with the rest of the population of people with renal failure. Only 2% of the general population have a learning disability (Emerson & Hatton, 2008), and the prevalence of chronic kidney disease in adults aged 18 and over in the UK is 4.1% (NHS Kidney Care, 2010). Whilst the figures for the number of patients with a learning disability and chronic kidney disease are not known, we may postulate from the other prevalence figures that the number will be quite low. Although these individuals are fewer in number, as the literature review has seen they may have presentations that are more complex in nature and each individual may bring challenges and differences (such as communication ability) that the medical team will need to work with. The literature review has discovered a paucity in the research base regarding learning disability and chronic illness. Because the researcher hoped to gain as much rich and detailed information as possible in order to answer the research questions, a qualitative approach was deemed most appropriate. The research questions/topics are broad, and encompass the themes (such as learning disability, chronic illness, and coping with renal failure and dialysis) discussed within the literature review.

10 participants (5 parents/carers and 5 consultant nephrologists) were interviewed. The study includes triangulation by interviewing both consultants and family/carers, in order to gain a more comprehensive view and greater understanding of how chronic kidney disease and its treatments are dealt with by patients with a learning disability. The interview transcripts were analysed using grounded theory and two models of

how patients with a learning disability cope with chronic renal failure (from the point of view of the consultants and family/carers) have been produced.

The method section now continues by considering the ethical aspects of the research, the recruitment of participants, the method of data collection and the method of data analysis.

## **4.2 Ethical Considerations**

### *4.2.1 Ethical Approval*

Initially, ethical approval was obtained for the study (which included the interviewing of consultants and patients with a learning disability) from the Bradford Research and Ethics Committee, and the Leeds Teaching Hospitals NHS Trust Research and Development Department (copies of the approval letters are included in the appendix 1).

When initiatives to recruit and interview patients with a learning disability were not successful, a major amendment was applied for in order that families/carers of patients with a learning disability could be interviewed. This amendment was approved by the Bradford Research and Ethics Committee and the Leeds TH NHS Trust R&D Department (copies of the approval letters are included in the appendix 1).

### *4.2.2 Internal Confidentiality*

There are issues that need to be taken into account when interviewing and analysing data from two groups that are somehow related. One important issue is that of internal confidentiality. Tolich (2004) wrote about this, comparing confidentiality to an iceberg; the tip is easier to see and he labels this as 'external confidentiality'. External

confidentiality is well known to all researchers and is where the participant is promised anonymity in the research and report so that external parties will remain unaware as to who has taken part or who has made various comments. However as Tolich writes; 'what lurks unseen, below the surface, is also a source of potential harm' (p101). He likens this to internal confidentiality. Internal confidentiality is how the participants' connected relationships to each other can lead to impaired or diminished autonomy within research. For example, one participant may recognise another from a quote used to illustrate a theme within the report - not from their name being printed, but from what was said or how it was said. The participant who has been quoted has then lost their internal confidentiality, and their relationship with the other participant who identified them may then be altered as a result. Participants may also worry that if they can identify themselves from the quotes that others may too. This paper by Tolich and the points and concerns he raises about internal confidentiality are significant, and the researcher has endeavoured to be aware of internal confidentiality and to maintain a constant vigilance when writing up this study. It is the aim of the researcher that any quotes used do not contain any potential identifiers so that one participant may not recognise another.

### **4.3 Participant Recruitment**

Initially the project aimed to recruit five consultants and five patients with a learning disability and a diagnosis of stage V kidney disease. Unfortunately it was not possible to recruit patients, so family members/carers were recruited instead. Whilst the researcher realises that the accounts of how an individual may cope told from another's point of view may not capture the true experience as felt by the individual, it was hoped that interviewing the families and carers of the patients (who have witnessed their experiences and coping close hand) may offer further insight and understanding as to how these individuals cope. The interviewing of the families is not seen as a straight forward replacement by the researcher; rather they are an additional group of participants that provide a different viewpoint and potentially

important data that will help to answer the questions and aims of this research. This participant recruitment section will now detail the inclusion/exclusion criteria for the consultants and family/carer participants before describing in more detail the participant recruitment process.

#### *4.3.1 Inclusion Criteria*

For Consultants:

- The consultant works in the renal service of a Teaching Hospitals NHS Trust.
- The consultant has previous or current experience of treating patients with a learning disability diagnosed with stage V renal failure.

For Family Members/Carers:

- To have a family member or care for/support someone with a learning disability who has been diagnosed with stage V renal failure.
- Have capacity to consent to participate in the study.

Time since diagnosis was not used as inclusion criteria. This was for two reasons:

1. To optimise participant recruitment.
2. When Stage V renal failure has been diagnosed, this indicates a stage has been reached where major decisions and life altering treatments are being experienced. Therefore stage of renal failure, rather than time since diagnosis of renal failure, was used as inclusion criteria.

The definition of learning disability as used by the Department of Health (2001a) was operationalised in this study. This definition was included in the information sheet

written to help the consultants identify potential participants (a copy of which is in appendix 2). Specific sub-diagnoses of learning disability (for example: borderline, mild, moderate, severe and profound) were not included in the inclusion criteria, or operationalised during attempted patient recruitment, for a number of reasons:

1. Individuals with a severe to profound learning disability are more likely to have difficulty communicating verbally, and are less likely to have the capacity to consent to the study. Unfortunately it was beyond the scope of this study (both in terms of time and finances) to attempt to rectify this, for example by developing communication systems or attempting to build-up relationships with individuals with a severe learning disability over extended periods of time.

This meant that the participants most likely to be recruited would have been patients with a mild to moderate learning disability. Difficulties arise in trying to specify level of disability within this range as:

- I. There can be difficulty in identifying the presence of learning disability in individuals (as noted by the consultants). Therefore it is likely that being able to identify the actual degree of learning disability would be more difficult. For example, factors such as an individual's verbal ability not always correlating with IQ level can make this difficult.
- II. In order to be specific about the level of learning disability an individual has, IQ tests would have needed to be administered. This has ethical implications for the study and the participants, and would not have been feasible for this research.

Therefore instead of focusing on specifying the degree of learning disability, the inclusion criteria regarding learning disability consisted of there being one present, as defined by the Department of Health.

#### *4.3.2 Exclusion Criteria*

For Consultants:

- The consultant does not work for the Teaching Hospitals NHS Trust.
- The consultant does not or has not had experience treating patients with a learning disability diagnosed with Stage V renal failure.

For Family Members/Carers:

- The individual has not supported someone with a learning disability diagnosed with stage V renal failure.

#### *4.3.3 Recruitment Process*

##### *4.3.3.1 Patient Participants:*

Around 2% of the population are estimated to have a learning disability (Emerson & Hatton, 2008). It might therefore be expected that a similar proportion of patients may attend the renal service. There are factors that may affect this number: persons with a learning disability are more likely to experience problems with their health; however people with a learning disability experience inequalities when it comes to accessing healthcare services and receiving treatment. What was known upon embarking on this research project is that the Teaching Hospitals NHS Trust is the largest regional renal service in the United Kingdom and the research team felt confident that patient participants would be found to take part.

The research team for this study included a consultant nephrologist. This consultant liaised between the researcher and the other consultant nephrologists that worked

within the department. All the consultants that work within the renal service were asked to name the patients they believe met the inclusion criteria, and to share this information with the liaison consultant (the researcher was not given this information due to data protection). In order to aid the consultants in this task, an information sheet regarding identification of individuals with a learning disability and capacity was emailed to each consultant (a copy of this information sheet is in the appendix 2).

Once the names of potential patient participants had been identified and passed to the liaison consultant, the consultant then accessed the patients' notes, and searched for indicators to confirm that the patient has a learning disability. Such indicators included written statements that the patient has a learning disability within the notes, previous engagement with learning disability services, previous attendance at a special school or a special educational needs statement or a learning disability assessment (such as an IQ score).

Accessible information and consent sheets and carer information sheets were then sent to the possible participants. The Leeds Service User Involvement Group (LSUI group) played a key role in the making of these sheets. The Involvement Group is made up of individuals with a learning disability that access healthcare and mental health services in Leeds, and some paid professional members of staff. The group plays an important role in producing and making information accessible for patients; they offer help and support to the NHS and health services in making their information accessible, and in helping them to evaluate and improve their services for patients with a learning disability. More information about the group can be found at [http://www.leedsmentalhealth.nhs.uk/our\\_services/ld/sui](http://www.leedsmentalhealth.nhs.uk/our_services/ld/sui).

The researcher met with the group on a number of occasions: they offered initial advice about how to write and format accessible information for people with a learning disability. The group then met and worked with the researcher formatting the sheets to make them as accessible as possible. The group showed the sheets to some service users that attend the group, who confirmed that they found the information



and consent sheet understandable. An additional short 'information about consent' sheet was also constructed. This would have remained within view of the participant during the interview.

The information and consent sheets clearly outlined two ways that the participant (or their carer) could have contacted the researcher: by telephone, or by sending their details to the researcher in a provided stamped-addressed envelope.

Of the packs of information sent out to potential participants, two parents replied on behalf of their children. They reported that they felt the level of learning disability that their child had was too severe for them to take part, but that they would like to tell their child's story on their behalf. The researcher then began to investigate and plan to interview parents and carers.

#### 4.3.3.2 Reflection upon Including People with Learning Disabilities in Research:

Before the method section discusses the recruitment of the consultants and families/carers, the researcher would like to reflect upon the following learning point: how important it is to include people with a learning disability in research that is about them. The initial aim of this research was to involve and interview patients with a learning disability. As described above, the researcher made significant attempts to recruit patients with a learning disability to this study. During this process it became increasingly clear to the researcher that despite the difficulty experienced in trying to recruit patients with a learning disability, the inclusion of individuals with a learning disability in research that is about them is of significant importance and worth extended efforts to engage and recruit. Below is a brief review of the literature base discussing why inclusion of participants with a learning disability is so important.

The inclusion of people with learning disabilities as participants within research is important. More specifically, their inclusion within *qualitative* research is important.

Historically, this participant group has not been included in research. One concern is that the participants may not have a 'good-enough' communicative ability to provide data for analysis. Researchers may also find it more 'accessible' to interview the families, carers and staff involved with the participants (instead of the individuals with the learning disability themselves) often due to the ethical concern of obtaining informed consent. Indeed, obtaining consent to participate in research can pose a particular ethical challenge for researchers. There are a number of concerns that can exist (Cameron & Murphy, 2006); ensuring participants understand the nature of participating in the research but at the same time avoiding coercion, and the concern that researchers either exclude people with a learning disability or include them without their consent. However, rather than avoiding research because of this, some imagination, care and preparation by the researcher can help the participants to understand the nature of the research and the implications of their participation, and to be in an optimum position where they may be able to give informed consent (for example, by making information accessible, using visual imagery and other communication aids, involving individuals with a learning disability in the planning of the research and so on). Gilbert (2004) suggests that the challenges in involving individuals with a learning disability in participating in research can be seen as lying within the inadequacy of the methodology, as opposed to being seen as a problem within the individual.

Over the past decade, the importance of the inclusion of people with learning disabilities within research has been recognised. Central to the argument is the civil human right to have 'free speech'. The concern is that by denying these individuals the opportunity to participate in research, you are denying them the opportunity to speak out and to have a voice.

It is also becoming evident how useful *qualitative* research as a method is in obtaining rich and useful data. Duckett and Fryer (1998) argue that the experiences, feelings and thoughts of individuals with a learning disability can be accessed using qualitative methods, and that unlike standardised quantitative techniques that more than often

require a high-level of communicative ability in order to retrieve insightful data, qualitative research enables individuals with a learning disability to have a voice. Atkinson (2004) agreed with this evaluation of qualitative research but believes that qualitative research with people with learning disabilities can be taken a step further and that it can, in fact, be empowering. Research that enables the participants to recall, recount and review their lives in depth is considered to be empowering; it treats the participants as 'expert witnesses' in the matter of their own lives. She argues that the participants can gain subtle benefits in being the author of their own story. Gilbert (2004) also argues for the empowering nature of research and adds that "this final issue [of research values] encourages NHS ethics committees to draw away from protectionism and recognise the empowering potential of participatory research" (p298). Brewster (2004) agrees and states "the genuine participation of people with learning disabilities in research about them is imperative" (p166). This is now reflected in the growing movement for participatory research, and in influential papers and legislation, for example Valuing People (Department of Health, 2001a) insists on participation in the policy implementation and evaluation process.

#### 4.3.3.3 Consultant Participants:

An email detailing the project with an information sheet was sent around the service to the eight consultants who work there, requesting volunteers. Five responded and arrangements for the interviews with these consultants were made.

#### 4.3.3.4 Family/Carer Participants:

Information sheets were sent to potential family and carer participants of patients known to have a learning disability and stage V kidney disease. The families were contacted and informed when the parameters of the study changed to include family members and carers as participants. Interested families responded and arrangements

for the interviews were made. There were seven potential families; it became apparent one family was not appropriate for the study (the reason why to be kept confidential), and another family reconsidered reporting that they were too busy to take part. Five families/carers were then interviewed.

## **4.4 Method of Data Collection**

### *4.4.1 Semi-Structured Interviews*

Semi-structured interviews were carried out with both the consultants and the families/carers. Copies of the consultant and family/carer interview transcripts are included within the appendix (appendices 7 & 8). It was initially decided that individual semi-structured interviews would be the most appropriate method of data collection for patient participants and consultant participants. Other methods of data collection that were initially considered and rejected included postal questionnaires and focus groups. Although this decision was made at the beginning when considering how to obtain data from learning disabled participants and consultants, the reasoning behind the choice is still important. These reasons are also why semi-structured interviewing remained the method of choice for obtaining data from family/carer participants.

For the purpose of this research, it was decided that postal questionnaires would not be an appropriate method of collecting data from participants who have a learning disability. They may not be able to express their opinions optimally by writing them, as compared to verbally expressing them through conversation. A number of items in the questionnaire may need explaining to participants, and they may need help filling in the questionnaire. In addition, a postal questionnaire could possibly be filled in by another person (such as a carer), without the researcher knowing, even though it may be addressed directly to the participant. Finally, traditionally, there is a low response rate to questionnaire surveys, and the catchment area would have to be widened

considerably in order to obtain the requisite number of cases. This would involve further ethical consents and a considerably larger number of consultant nephrologists. Postal questionnaires would not adequately achieve the richness of data that can be obtained from interviewing the consultants or family members/carers either.

It was also decided that focus groups would not be an appropriate method of obtaining data for this research project; people with a learning disability have very individual competencies with regard to language and conversation and it is unlikely that all learning disabled people in a focus group would experience the same degree of success and satisfaction in delivering their views. It was decided that it would have been more productive for the participants to be interviewed as individuals, to answer a number of questions relevant to the inquiry and to be encouraged to speak freely about their experiences. A focus group for the consultant or family/carer participants would not be the most appropriate method for obtaining their views and experiences either; the consultants may wish to share sensitive or difficult experiences or opinions (for example, instances where they have decided that a patient would be unable to cope with dialysis, or concerns about the quality of service). They may be more unlikely to share such views in a group of their peers and fellow co-workers. Similarly, it may be that family members may feel uncomfortable talking about difficult experiences in front of others; for example, a parent may avoid talking about how traumatic dialysis is or how overwhelming it felt when a transplant failed in their child knowing that there may be parents of someone waiting to start dialysis or waiting for a transplant in the group.

Through their very nature, semi-structured interviews provide some structure and guidance to the researcher as to what information would be most useful to obtain in order to answer the research questions, whilst still allowing a crucial freedom for the researcher and the participant to explore any additional areas that are felt to be important to the participant, in more depth. This provides data that is relevant, rich in content, prioritised by the participant and explored further by the researcher. These benefits of the semi-structured interview (Charmaz 2006) coupled with the

disadvantages of the other methods of data collection (postal questionnaires and focus groups) make semi-structured interviewing the method of choice for data collection.

#### *4.4.2 Interviewing the Consultants*

The interviews with the consultant nephrologists were conducted at St James' University Hospital. Arrangements were made to meet the consultant at a convenient time.

At the beginning of the interview, the researcher and participant talked about the study. The participant read the information sheet and completed the consent process and consent form. Copies of these sheets can be found within the appendix (appendices 3 &5). The interview then commenced. The interviews lasted from thirty five minutes to seventy five minutes in duration (the majority lasting an average of sixty minutes).

Below is some basic demographic information for the consultants interviewed (the data have been re-arranged in each column in order to protect the consultants' identities):

<b>Gender</b>	<b>Age</b>	<b>Length of Time as Consultant (years)</b>
Male	46	7
Male	51	17
Male	55	8
Male	46	20
Male	41	12

**Table 2-4. Demographic information for the Consultant participants.**

#### *4.4.3 Interviewing the Family/Carer Participants*

The families/carers of the initial list of possible patient participants were contacted by the consultant nephrologist who explained that the parameters of the study had changed, and that the researcher now wished to interview and include family members and carers. Following a positive response from interested family members/carers, the researcher and potential participant made arrangements for the interview. Each participant was offered the choice to be interviewed in their home or at the hospital (which ever was most convenient for the participant). Every interview actually took place in the participants' home, so the lone worker policy as set out by the University Of Leeds Institute Of Health Sciences was followed by the researcher.

At the beginning of each interview, the researcher and participant talked about the study. The participant read the information sheet and completed the consent process and consent form. Copies of the sheets can be found within in appendix (appendices 4 & 6). The interview then commenced. The interviews lasted an average of one hour.

After the interview had finished, the researcher repeated the confidentiality and data storage policy.

Below are tables depicting the characteristics of the patients described by their families/carers, in order to aid understanding when reading the results section (the data have been re-arranged in each column in order to protect the patients' identities):

<b>Participant relationship to patient</b>	<b>Patient sex</b>	<b>Patient age</b>	<b>Level of LD as described by participant</b>
Mother and father	Male	31	Mild
Father	Female	77	Severe
Mother	Male	52	Moderate
Aunt	Male	40	Mild
Service manager	Male	38	Severe

<b>Dialysis</b>	<b>Length of time in Stage V renal failure (years)</b>	<b>Transplant</b>	<b>Any additional diagnoses</b>
Peritoneal Haemodialysis	1	One	Needle phobia OCD Autistic Spectrum
About to start haemodialysis	Unable to remember (over ten)	No	Spina Bifida.
Haemodialysis	2	Two	Autistic spectrum Previous myeloma.
Haemodialysis	6	No	-
Haemodialysis	5	Considering	Cerebral Palsy

**Table 5-12. Characteristics of the patients described by the family members/carers.**



## 4.5 Method of Data Analysis

### *4.5.1 Introduction to Grounded Theory*

Grounded theory was chosen as the method of analysis of the interview data. Grounded theory is designed to facilitate the progress of discovery and theory generation; theories emerge from the data, rather than the data fitting into previously determined themes or categories. Grounded theory does not test a hypothesis; instead it sets out to understand the research situation and to discover the theory implicit in the data. It is responsive to the research situation, and is driven by the data in such a way that the final theory will explain what is happening. This is a major factor as to why grounded theory was the chosen method of data analysis. The advantage of grounded theory is that it is by its nature model and theory building. How patients with a learning disability cope with chronic renal failure and its treatments was not known and there were no current models. This research has contributed to theory development in this area.

Grounded theory has been used previously to aid understanding of chronic illness. Starks and Trinidad (2007) compared three qualitative approaches that are used in health research; phenomenology, discourse analysis and grounded theory. The analytic approach chosen shapes how the research questions are framed, how data is attended to and its meaning (p1373). For example, the goal of phenomenology is to describe the meaning of a lived experience, to produce a thematic description of the structure of experiences. The goal of discourse analysis is to understand how people use language to create and enact identities and activities, to produce a description of language-in-use and identify how different discourses shape identities and relationships. The goal of grounded theory is to develop an explanatory theory of social processes, generating a theory from the participants' experiences. It is the latter goal and production of grounded theory that best helps us to understand how patients with a learning

disability cope with renal failure (through the perception of their family/carers), and whether this is comparable to how consultants believe patients cope.

#### *4.5.2 Ontological and Epistemological Assumptions Underpinning Grounded Theory*

A concern sometimes made regarding grounded theory is its ontological and epistemological foundation (Willig, 2008). Ontology concerns the nature of reality; what the form and nature of reality is, and what can be known about reality (Annells, 1996). Epistemology is defined by ontology and is concerned with the nature of the relationship between the knower and what may be known. Finally, methodology is influenced by both ontology and epistemology and describes how researchers ascertain what they think there is to be known and the process by which they plan to acquire this knowledge.

It has been argued that the traditional approach to grounded theory (as set out by Glaser & Strauss, 1967) has a positivist epistemology, and that this positivist approach allows grounded theory to ignore the researcher's reflexivity. The original aim of grounded theory is that theory emerges from the data; one implication of this is that the researcher is seen as an observer, separate from the data and objective. This is known as positivist epistemology. Positivist epistemology assumes that there is knowledge to be known, and that the researcher is a neutral observer who discovers data in an objective way. Glaser and Strauss subsequently disagreed about the direction of grounded theory. Glaser argued that theory should only emerge from the data itself and that the researcher should never impose their own theoretical interpretation upon it, whilst Strauss and colleagues (such as Charmaz, 2006) offer a more pragmatic view about the role and influence of the researcher in structuring the research findings; that of constructionist grounded theory.

Constructionist grounded theory attempts to answer the concerns raised about the positivist approach regarding the influence of the researcher's reflexivity. A

constructionist approach believes that there is no singular 'true reality' to be known; the social world is constructed through language and meaning that is developed and shared through social interaction. The ontology of constructionism therefore is that there is no objective reality; realities are social constructions of the mind (Ghezelijeh & Emami 2008, p17). The epistemology of constructionist grounded theory is that knowledge is created through the interactions between the researcher and what is researched. In short, the researcher cannot be separated from what can be known. Instead of theory simply 'emerging' from the data, the theory is constructed by the researcher through the research process.

This research was approached using constructionist grounded theory methodology; the patients' families and consultants, through their own daily interactions with others, will have led to them constructing their own set of beliefs around coping. These constructs will result in actions that the patients, families and consultants make. As the researcher I tried to maintain awareness of my reflexivity, because as Charmaz (2006) says, my own questions and constructs around illness and coping may themselves have interacted and partly shaped the analysis. It is important to reflect and think about this during analysis, because as Burr wrote, there is no 'objective, unbiased observation of the world' (p2). The use of memo writing and a reflective research journal helped me to maintain my awareness and to reflect upon any responses I may have had, or any interpretations I may have found I had been making (an example of a memo can be found later in the method section).

#### *4.5.3 Constructionist Grounded Theory*

Charmaz has written a pivotal paper describing and promoting the use of grounded theory as a method of qualitative analysis in understanding chronic illness experiences, and in particular, the use of social constructionist grounded theory (Charmaz, 2006). She describes that when using the grounded theory method, "the questions that researchers put into the world, how they collect their data, and which issues and

processes they see within it all fundamentally shape their analyses” (p1170). She argues that because grounded theorists study process, they realise that theories cannot be frozen in time and that grounded theory analyses can be adapted to changing conditions. She concludes that:

“Using grounded theory to study chronic illness offers the researcher strategies for focusing and controlling large amounts of data in ways that render it conceptually and, in turn, move the emergent conceptualisations toward more general theoretical statements. Such statements not only deepen sociological understanding of the experience of chronic illness, but also, contribute more generally to the discipline” (p1170).

The analysis will be grounded from a social constructionist view point.

Vivien Burr(1995) describes social constructionism as having at its foundation a number of key assumptions (p2):

- A critical stance towards taken-for-granted knowledge: we must take a critical stance towards our ways of understanding the world, including ourselves, and challenge the view that conventional knowledge is based upon objective, unbiased observation of the world.
- Historical and cultural specificity: The ways in which we understand the world, and the categories and concepts we use are historically and culturally specific, and are dependent upon the particular social and economic arrangements prevailing in that culture at that time. We should not assume our ways of understanding are any better than other ways.
- Knowledge is sustained by social processes: The daily interactions that occur between people in the course of life construct our common understandings of the world. Our current understanding of the world is a product not of objective observation, but of social processes.
- Knowledge and social action go together: Each different construction can bring with it a different kind of action from human beings.

#### *4.5.4 Reflexivity of the Researcher*

It is important within qualitative research, especially when utilising a constructionist grounded theory methodology, to describe the reflexive position of the researcher. The position of the researcher and their role can and will affect and shape the research in various ways, from sampling decisions, analytic technique, to interpretations of context and meaning. It is therefore important to describe the researcher's reflexive position so that readers are aware of it and take this into consideration when reading the study.

I am a trainee clinical psychologist in the final year of clinical psychology doctorate training. Prior to beginning training I worked with people with learning disabilities for a number of years (as a support worker and as an assistant psychologist), and enjoyed doing so. I later worked as an assistant psychologist at Alder Hey Children's Hospital, where I first became interested in health psychology. When thinking of a subject of investigation for my thesis, I hoped to combine my two areas of interest; learning disability and health. I met with my two supervisors (one of whom works in learning disability, the other in health psychology); we all agreed learning disability and health would be an important area to investigate. One supervisor works in the renal unit of the hospital involved in this study. When he mentioned the research to the renal staff, they expressed interest and enthusiasm in being involved; the thesis topic was then decided.

I also have personal experience of learning disability and renal failure through my family; I have a younger sister who has previously had dialysis and now has a successful transplant, and another sister who has a learning disability. On reflection I have no particular expectations regarding access and experience of healthcare services; my sisters have experienced healthcare that they have viewed as being of good quality, and episodes of care that they have felt to be of less quality. It is important to note that my experiences are to an extent separate in that they are not of

those of a person with a learning disability accessing renal services. I believe my personal experience has motivated me and my wish to produce good quality research. It also aided me in that the terminologies of disability and medicine were easier for me to use and understand, although it was important that I was aware of not assuming my knowledge and understanding of a term was the same as the participants'. For example, if a family participant asked if I knew what peritoneal dialysis was, I would answer 'yes, but what does it mean for you and X?' I found the use of a reflective diary and memos to be instrumental in helping me to maintain my awareness of my role and how my beliefs and values may have shaped the research. My hope in carrying out the research was to begin to explore this important but as yet relatively unexplored research topic. My hope as a researcher was to find out anything and everything there may be about how patients with a learning disability cope with being chronically ill. With this in mind, my wish to explore may have shaped the research questions, interviews and analysis in terms of wanting to find out as much as possible about this topic. For example, the research questions are broad and encompass a number of themes discussed in the literature review. Similarly, in the interviews the focus wasn't necessarily strictly upon renal failure; when families/consultants spoke of other factors such as additional diagnoses or the importance of social support, these areas and their effects upon coping were explored further.

#### *4.5.5 Alternative Methods of Analysis Considered – IPA*

When selecting a method of data analysis, it is important to consider other methods to ensure the one selected is the most appropriate. The other main theory of analysis considered for this study was Interpretive Phenomenological Analysis (IPA). IPA aims to gain an understanding of how an individual experiences and views their world. It believes that an individual's accounts allow insight into their thoughts and beliefs.

IPA is similar to grounded theory in some ways; as Willig (2001) describes, both work by systematically going through text and sorting the information into themes or

categories, integrating them until higher-order units are found. Both use categorisation to achieve systematic data reduction. Both aim to produce a type of 'cognitive map' that represents an individual's or group's experience/view of the world. Finally, both begin with individual cases, with the aim of being able to build a composite picture that explains more than any individual case might.

However, IPA is used specifically to look at the individual experiences of the participants themselves. In this study the participants describe not only their own experiences but those of an individual with a learning disability. Accounts and beliefs of what other people experience are better suited to analysis by grounded theory, rather than IPA which focuses on the individual.

Additionally, unlike Grounded Theory, IPA does not produce a theory or model that emerges from the data. As evidenced in the literature review above, the previous and current psychological models of coping with and adjustment to chronic illness do not take into consideration the possible effects of having a learning disability, and they are indeed likely to be influenced and changed by the presence of a learning disability. It would provide valuable insight if a model emerged from the data obtained in this project; hence grounded analysis is the most appropriate choice of analysis as it has allowed two theories to emerge.

The method section has considered and explained why grounded theory is the most appropriate method of data analysis for this project, and has given an introduction to the theory and the evidence-base behind it. The method section now continues with a more in-depth look at the process of the grounded theory analysis that occurred, providing examples of coding and memo-writing.

#### 4.5.6 *The Process of Grounded Theory - Coding*

The general process of grounded theory analysis is the assignment and labelling of categories or key-issues that emerge from the interview data. Analysis begins after the first interview, and continues after each interview takes place.

*Coding* is the process by which categories are identified. As Charmaz (2006) describes:

“Coding means categorising segments of data with a short name that simultaneously summarises and accounts for each piece of data. Your codes show how you select, separate, and sort data to begin an analytic accounting of them”(p43).

The first stage of coding is initial coding which is largely descriptive in nature and closely resembles the data. Charmaz recommends trying to see actions in the data, rather than attempting to apply pre-existing categories; it is at this point, at the beginning of the coding process, that the researcher remains open to exploring whatever theoretical possibilities there may be within the data (p43), and many new ideas may emerge. The open codes are provisional (the researcher remains open to other possibilities or differently phrased codes), comparative and strongly grounded in the data (p44).

As the coding progresses, the initial codes become more focused codes. Charmaz (2006b) describes focused coding as:

“Focused coding means using the most significant and/or frequent earlier codes to sift through large amounts of data. Focused coding requires decisions about which initial codes make the most analytic sense to categorise your data incisively and completely”(p57).

At this stage, coding becomes more selective and conceptual. Instead of explaining data word-by-word or line-by-line, the focused codes are able to represent larger



sections of text. The most frequent and significant codes discovered in the initial coding process are used to sort through larger sections of data, and their appropriateness as focused codes decided upon. The focused code is developed through comparing data to data, and then the data is compared to the focus codes in order to refine them (p60).

Axial coding relates subcategories to categories. Charmaz (2006) defines axial coding as:

“Axial coding relates categories to subcategories, specifies the properties and dimensions of a category, and resembles the data you have fractured during initial coding to give coherence to the emerging analysis”(p60).

Axial coding brings the data back together to begin to explain what is happening overall. Axial codes are able to answer who, what, why, when, where and how, and they specify the properties and dimensions of a category (p60).

The final level of coding, often viewed as the most sophisticated, is the theoretical coding. Charmaz (2006) describes theoretical coding as:

“In short, theoretical codes specify possible relationships between categories you have developed in your focused coding...These codes may help you tell an analytic story that has coherence. Hence, these codes not only conceptualize how your substantive codes are related, but move your analytic story in a theoretical direction” (p63).

It is from these theoretical codes that the theoretical diagram or model is produced.

To summarise the coding process, initial coding breaks down and analyses the data in small pieces. This provides the backbone of the analysis by making sure that the codes emerge from the data itself, rather than fitting the data into preconceived ideas of what might be happening. Focused coding begins to draw out some of the more significant codes which can be used to explain larger sections of data. Axial coding then reassembles the data and its explanation back into a whole, linking subcategories to

categories. Finally, theoretical coding guides the last stages of the analysis into the production of the final theoretical diagram/model.

During the analysis process, the researcher used a large whiteboard and coloured Post-It™ notes (a colour for each participant) to note codes. The codes were then stuck to the board. Using the board allowed the researcher to more easily see emerging groups and to move around the notes as appropriate. It also gave a visual indicator as to which themes were discussed the most by the participants. Photographs that illustrate the process are in appendix 9.

The following table demonstrates a section of interview transcript, from an interview with a consultant, which has been coded:

Quote	Initial Coding	Focused Coding	Axial Coding	Theoretical Category
<i>Well, it [time on dialysis] depends on how far away you live and how long</i>	Dialysis time is affected by distance between home and hospital.	Factors affecting dialysis experience.	Demands of dialysis.	Demands of treatment.
<i>transport takes you but yes it could easily be you know</i>	Dialysis time is affected by hospital transport.	Factors affecting dialysis experience.	Demands of dialysis.	
<i>usually getting on for a four hour treatment and depends</i>	Dialysis lasting four hours.	The dialysis experience.	Demands of dialysis.	
<i>on how long the transport takes at either end and you</i>	Dialysis time is affected by hospital transport.	Factors affecting dialysis experience.	Demands of dialysis.	
<i>often feel pretty rough at the end of it as well, one of the</i>	Dialysis causing patient to feel unwell.	The dialysis experience.	Demands of dialysis.	

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<i>paradoxes is that if you can't</i>	Paradox of dialysis.	The dialysis experience.	Demands of dialysis.
<i>adhere to your fluid</i>	Importance of adhering to fluid restrictions.	Restricting fluids.	Demands of fluid restriction
<i>restriction and you gain a lot</i>	Non-adherence causes fluid weight gain.	Restricting fluids.	Demands of fluid restriction.
<i>of fluid weight between</i>			
<i>dialysis sessions then you</i>			
<i>need all that fluid removing</i>	Fluid needs removing during dialysis.	Mechanics of dialysis.	Demands of dialysis.
<i>during the dialysis</i>			
<i>treatment, and actually that</i>			
<i>makes you feel pretty awful</i>	Removal of excess fluid causes patient to feel unwell.	The dialysis experience.	Demands of dialysis.
<i>at the end of treatment.</i>			

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**Table 13. Example of the Grounded Theory Coding Process; an Excerpt from the Consultant Data**

#### *4.5.7 The Process of Grounded Theory – Constant Comparison*

Constant comparison is integral in grounded theory analysis; this is the constant comparing of data (the comparing of interview data with interview data, then emerging theory with interview data) that looks for similarities and differences between the emerging categories. As the analysis continues, links between categories and the identification of core-categories will occur. The links between these subcategories and how they relate to a core-category provides the theory.

#### *4.5.8 The Process of Grounded Theory – Memo Writing*

Memo-writing is a very important part of the grounded analysis process. Throughout data collection and coding, the researcher records memos (such as the definitions of categories, the justifications for terms used, the emerging relationships seen between categories and so on). The memos are informal, spontaneous and written in a way that the researcher finds comfortable, and are ultimately for the researcher's use. They are analytical in nature, and collectively form a written account of the production of the theory by providing information about the process and the findings of the research. Charmaz (2006) simply recommends that memos are written in whatever way works best for the researcher:

“Keep writing memos however you write and in whatever way advances your thinking”(p80).

Below is an example of a memo written by the researcher whilst analysing the consultant data:

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## Memo

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### Quality of life:

The consultants often spoke of 'quality of life' when thinking about and deciding whether patients with a learning disability should be put on dialysis. It feels like a balance for them – will the impacts of dialysis impact too much upon quality of life? Do the risks of putting a patient on dialysis (pulling out needles, tubes, becoming distressed, acting out) outweigh the patients best interests in terms of their health and survival?

Twice (so far) I seem to recall phrases like 'because his quality of life is good, we should offer dialysis'. Is there something about the perception of quality of life prior to dialysis that also influences whether dialysis is offered? Which leaves me thinking - who judges quality of life? What makes a good quality of life? How is it measured? The concept of quality of life (both current quality of life prior to dialysis, and potential quality of life whilst being on dialysis) seems to play a role in the decision-making process.

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**Table 14. An Example of a Memo**

### *4.5.9 Synthesis of the Models*

As this research has produced more than one model, the final stage of the analysis is to consider whether the two models should be synthesised into one model.

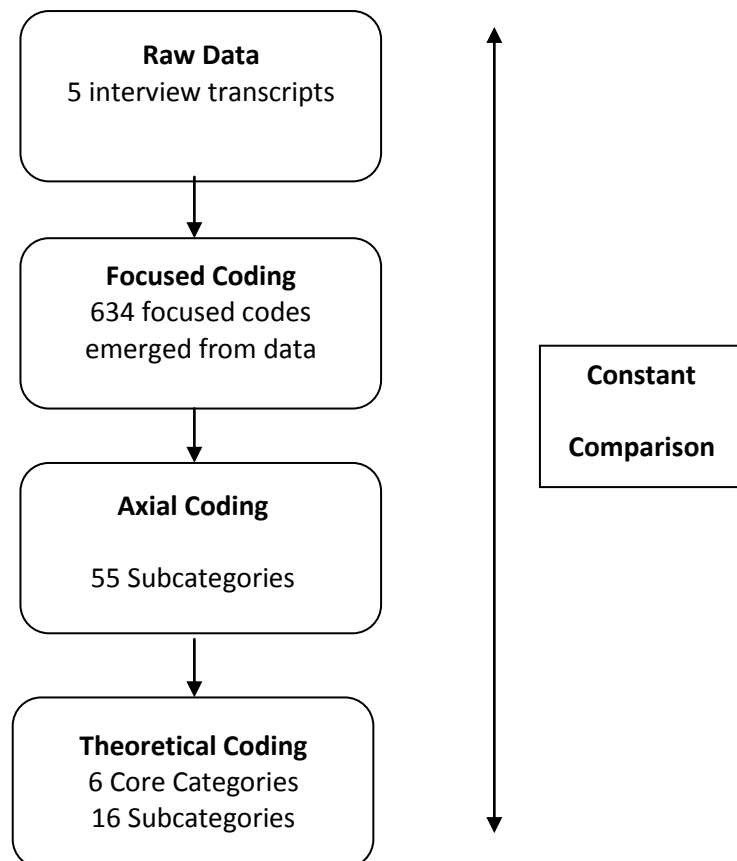
This method chapter has considered participant recruitment, data collection and how the data was analysed. The next chapter considers the results of the data analysis, and presents the two theoretical diagrams that have been produced.

## 5.0 Results

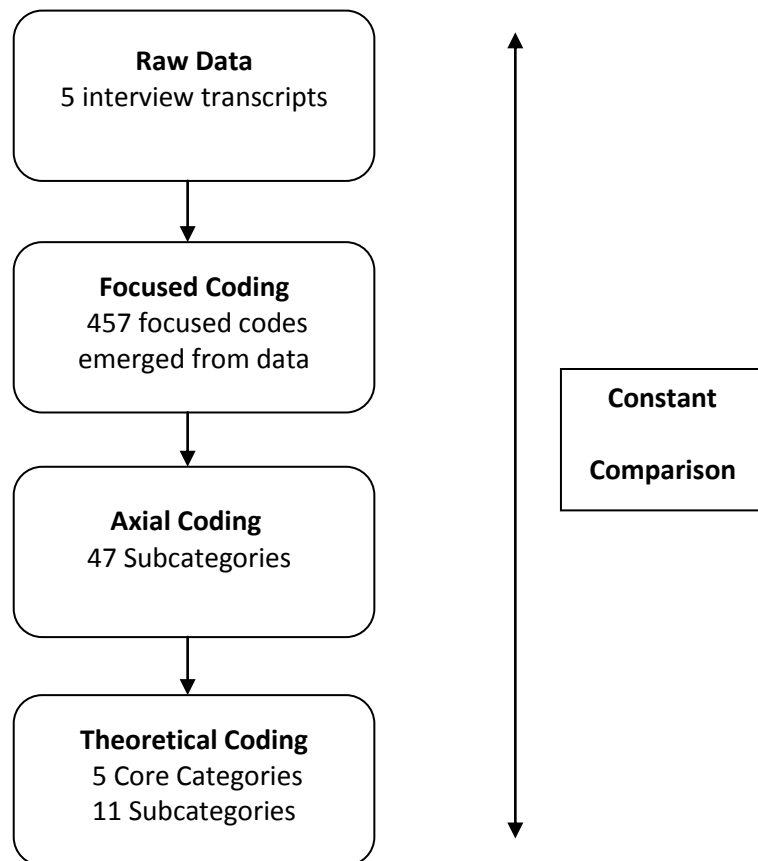
The results section begins with two illustrations summarising the analysis process for the consultant and the family data. It then describes the theoretical diagram of coping that has emerged from the consultant data, followed by an explanation of the coping theory derived from the family data.

The following diagrams illustrate the overall coding processes for the consultant data and the family/carer data:

The Consultant Data:



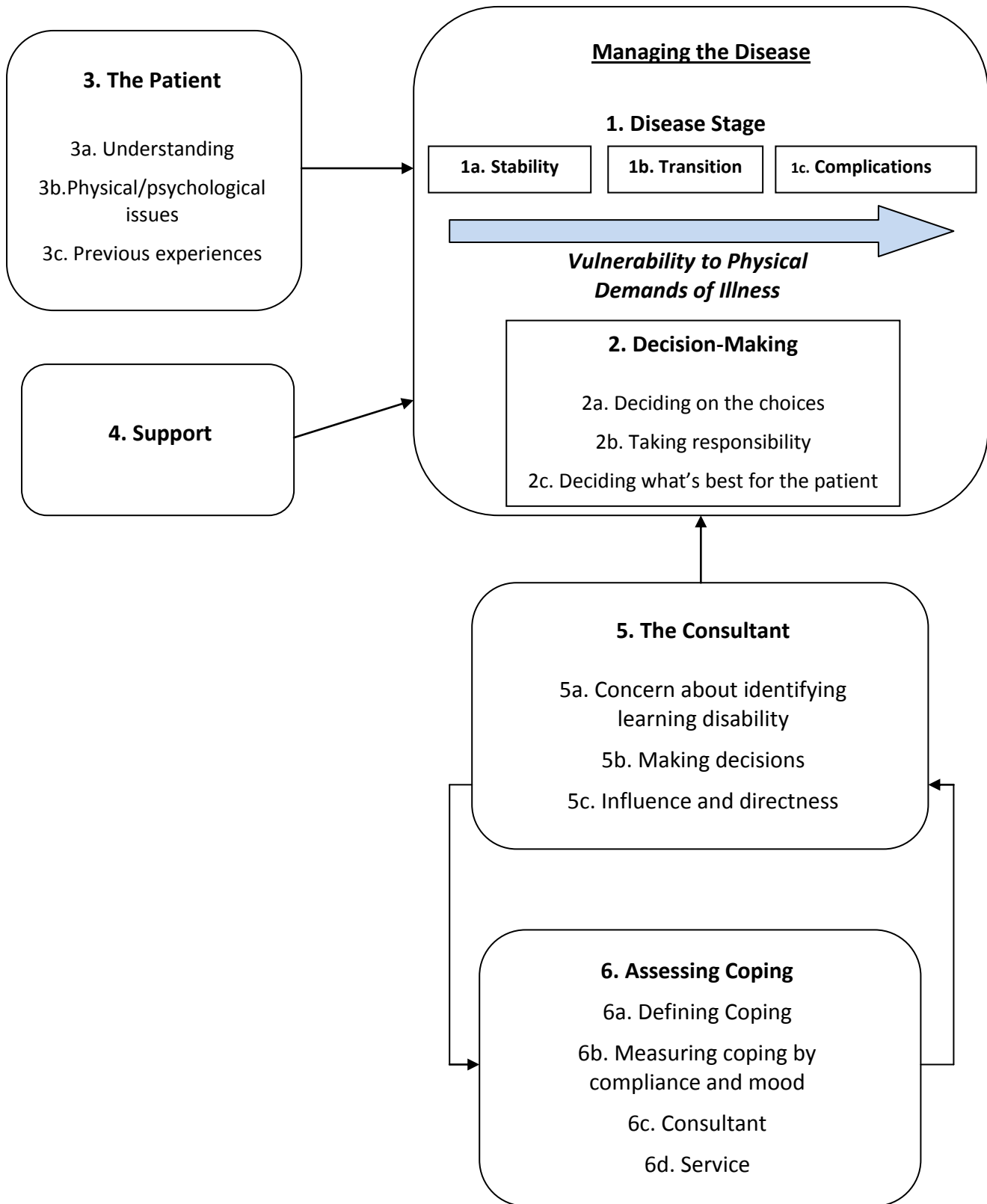
The family/carer data:



## 5.1 The Consultant Theoretical Diagram of Patient Coping

The theoretical diagram of coping derived from the consultant data is below:





**Figure 7. Theoretical Diagram of how Patients with a Learning Disability Cope with Kidney Disease - Derived from Consultant Data.**

The theoretical formulation of the consultants' views of patient coping consists of 6 core categories and 16 subcategories. The consultants often spoke of renal failure in stages; each stage brought different decisions, challenges and issues. It was the decision-making and the coping at each stage of the illness that appeared to be at the heart of managing the illness. The consultants spoke of the demands of the illness increasing in intensity depending on the stage; stability involved less demand as they found that the patient had been established on and adapted to the treatment routine. They believed transition involved more demand as difficult decisions were made and the patient had to adapt to the new treatment and their new lifestyle. Finally the experiencing of complications involved hospitalisation and additional procedures. The consultants often spoke of patients finding these extra procedures and extended stays in hospital overwhelming and traumatic; complications were often spoken of being the most demanding and difficult for patients to cope with.

Each consultant spoke of how the patient's experience of the illness and their management of it were affected by factors integral to the patient, their social support, and the actions of the consultant. The category of 'the consultant', which concerns the consultant's own decision-making and style of interaction, is a category detailing their own perception of what constituted good coping, in terms of the patient, the consultant and the service.

Before this results section continues with a more in depth description of the major areas of the theoretical diagram, a contextual factor was raised by a consultant that indicates a possible '*gateway*' to the service:

**Contextual Factor: *Referring to the Service***

**Description:** One consultant spoke of a particular concern he had; that there may be a referral bias of people with a learning disability with kidney problems not being referred to the service.

**Examples:**

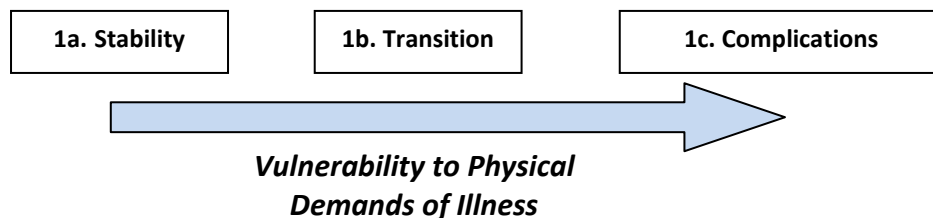
*Consultant04: “actually the number of people in a seventeen year consultant career...my impression is we see fewer people with learning difficulties than we would expect to”.*

*Consultant04: “It wouldn’t surprise me if there was a referral bias, that people don’t send the people to us and are thinking actually that the treatments are too difficult or we wouldn’t want them”.*

The results section now discusses the theoretical diagram in more detail. It begins by presenting a core category that has significant importance – that of ‘managing the disease’.

### **Core category 1: Managing the disease**

The first major area of the diagram is that of managing the disease, which consists of the consultants’ descriptions of the stages of the disease, the different issues and level of demands that each stage brought, and the decision-making process that the consultants found they often played a major role in.



#### ***Subcategory 1a: Stability***

**Description:** The consultants felt that when a patient became established on a treatment regime, there was an increased chance that they would adjust and cope better. The majority have found that for the patients, life falls into a more easily accepted and lived routine, especially in comparison to periods of transition or complication. Several noted that once a routine was established, patients with a learning disability actually had the potential to be better at managing their condition than those without a learning disability, following their treatment routine more diligently. Being in a period of stability meant that there were no new stressors for the

patient to cope with; there was less stress upon the body, and therefore less stress upon the mind.

**Examples:**

*Consultant03: "Once you've achieved stability then things are ok. But it can take a long time to achieve stability".*

*Consultant01: "But now she's established, it's all stable, all is working well, in the long term she is doing really well".*

*Consultant01: "And if you can get them into a new [routine] that's regular and becomes the new routine, then actually they'll be fantastically good patients, compliant patients...because they just want, you know, they just get the routine".*

*Consultant 01: "some patients with learning difficulties are the best drug takers, because they just want, you know they get the routine".*

**Subcategory 1b: Transition**

**Description:** The consultants said that typically within renal failure the transitions of most significance were those of beginning dialysis, stopping dialysis, switching forms of dialysis, or having a transplant. In stark contrast to their descriptions of periods of stability, the consultants have found that these periods of transition and change were difficult for patients with a learning disability to cope with. These transitions were life-changing; they caused increased physical distress, and increased psychological and emotional distress. It took time for the body and the mind to adjust so that the individual could begin to feel more stable again. During these periods of uncertainty the individual often felt vulnerable; significant changes (to themselves, their lives, their environment and so on) were happening that they may have felt physically and psychologically unable to understand and control. It therefore took some time before the individual felt more familiar with this new life; to feel safer, more secure and more in control.

**Examples:**

*Consultant01: "But I really don't think they cope well with, say, getting towards needing dialysis, switching to another form, being admitted for a line change, then thinking about a transplant, a really fast moving transition period I think they cope very very badly with".*

*Consultant05: "and the other girl who ended up having the transplant, I think the change is very difficult, from needing dialysis to not needing dialysis..."*

### **Subcategory 1c: Complications**

**Description:** The consultants described several case examples where the patient had experienced a number of complications. They believed that patients with a learning disability found complications significantly more difficult to cope with. There was a general feeling from the consultants that complications were the most difficult to deal with because of their consequences: they were unexpected and unplanned, caused extended stays in hospital and additional operations and procedures, and more than likely caused the individual to feel additional pain or to feel very unwell. Any person, regardless of learning disability, is likely to find it more difficult to cope with these physical and emotional consequences. The consultants did not discuss or go into detail as to how having a learning disability may have impacted on the experience of complications; one can postulate from the rest of the data (for example, the patients that have a severe needle phobia) that having a learning disability may mean an individual has difficulty understanding the purpose of extra, unknown and painful procedures. This in turn may cause distress and a behavioural desire to make the painful intervention stop. Similarly to the other stages of illness, coping with complications were affected by the other major categories. However, it appeared that it was the inherent nature of complications that made them so difficult to deal with. These complications came as a significant physical shock to the individual; they were suddenly feeling very physically unwell (nauseous and fatigued) and they often experienced high levels of pain. Such physical trauma had a significant psychological impact; the individual often experienced emotional distress, feeling fear, anger, helplessness and hopelessness. It was only when these major physical complications (the pain, nausea, fatigue) had gone that the individual was able to begin to psychologically recover.

### **Examples:**

*Consultant05: "So it was very difficult for her and she was in hospital for, you know if you took the 52 weeks of the year I guess she would have been in for about 20 weeks or something, not all in one, but in and out and in and out because of complications".*

*Consultant03: "...he was spending a lot of time as an inpatient in hospital with various problems and it was always impossible to discharge him because every time he came in there was some other reason that made it difficult for him to get back home again".*

*Consultant01: "...she didn't cope very well when the transplant didn't work very well to start with, she kept getting urine infections and kept having problems with the transplant, kept having to come in for operations, and she did just not cope with all that change very well".*

## **Core Category 2: Decision-Making**

Every consultant spoke of decision-making being integral to the management and experience of renal failure. The consultants spoke of the issues involved around what the options were, who made the decisions, and how they were made.

### ***Subcategory 2a: Deciding on the choices***

**Description:** The consultants talked about the treatment options that may be available for patients, including haemodialysis, peritoneal dialysis and transplant, and the further option of no treatment ('conservative care'). The first major decisions the consultants spoke of were those regarding the first treatment option; whether to go on dialysis and which form of dialysis. The decision as to whether the patient was placed on the transplant list also needed to be made. The decision-making also included an ongoing process of assessing and deciding how the patient was coping with the treatment, whether to continue with treatment, change to a different treatment, and how to manage and treat any complications that arose. As seen in the next category, the treatment choices considered were dependent upon a number of factors, one of which was whether the consultant and their family/carer thought they would be able to cope with the treatment. For example, haemodialysis requires that the patient is able to sit still for three to four hours (even keeping your arm still so the needle is not dislodged), attached to a dialysis machine via a needle. Some consultants expressed concern that due to not understanding what was happening or the necessity for it, individuals with a more severe learning disability may have been unable to sit still for such long periods, or may have been unable to allow the use of needles which

can be painful. If the consultant was significantly concerned that was the case, the option then became unavailable.

**Example:**

*Consultant03: "There's haemodialysis and peritoneal dialysis. Often when they've gone for dialysis, we've gone for the other type of dialysis PD, which can be done at home but you need support"*

*Consultant01: "We have had patients who can't dialyse basically because if you can't sit still on dialysis for three hours at a time, we can't sedate someone every time. So the patients with severe learning difficulties are sometimes not dialyzable and basically you have to proceed with conservative care and let them die basically".*

As illustrated in the quote above (and in some other quotes) the consultants spoke on a number of occasions about patients with a learning disability dying. Hearing such discussion sometimes caused an internal reaction in the researcher (such as feeling shocked). The training the researcher has had meant that instead of expressing her reaction, she was able to gently enquire about this topic further. It was through this investigation that the researcher realised how complicated the issues around treatment options and 'conservative care' can be. For example, one consultant spoke of a patient with a learning disability who hated being on dialysis. He would cry and become distressed every dialysis shift. His relationships with his support staff broke down as he was angry that they put him on the transport bus to the hospital. He repeatedly asked for dialysis to stop, but he also didn't want to die. The consultant spoke of him and the service feeling like they were 'torturing' this patient; they felt stuck and did not know what to do. To feel responsible for the 'ongoing torture' of someone is likely to be a heavy psychological burden to bear. It may therefore be important to consider the potential impact of this and of similar situations on the consultants and staff, and to perhaps also consider how clinical psychology may be able to provide a supportive role.

***Subcategory 2b: Taking responsibility***

**Description:** Every consultant talked about their role in the decision-making process. They reflected that in their experience, patients with a learning disability were often

unable to make decisions about their treatments and as a result the consultant and the patient's family/carers took on more responsibility and made the decisions for them. Whilst the consultants expressed awareness of their responsibility in the decision-making process, they also talked of the importance of the family/carer's role. As a few of the consultants noted, decisions were affected by and could change depending on who was involved, the strength of their views, and also perhaps their ability to argue them. It was generally felt that disagreement between consultant and family/carers was rare; but when it occurred (depending on the strength of objection and ability to argue) the decision was either changed, or the consultant may have needed to work harder to explain why the original decision was of best interest.

**Examples:**

*Consultant 04: "Well very often you're making important decisions about other people's lives for them actually"*

*Consultant 05: "My biggest work is for people before they need to have dialysis, therefore I'm helping them prepare, make choices between the different things, so it feeds into a worry about whether they have properly been involved I suppose in the decision. And one finds oneself being very reliant on the carers..."*

*Consultant03: "We had decided not to go for dialysis. Then he had a new key worker take on his case and she came to clinic with him one day and said 'Why? Why can't he have dialysis?' and really challenged me, really quite hard...and then we started talking about the pd option and that was when she started saying 'well that sounds alright, we could do that, it's not difficult'...and it worked really well".*

**Subcategory 2c: Deciding what's best for the patient**

**Description:** All the consultants talked about the decision-making process and what they have found to be important to consider when trying to make the best decision for the patient (often in conjunction with the carer). The consultants talked of trying to almost predict how and if the patient would be likely to cope with treatment demands and restrictions. They also often spoke of the importance of working out what was in the patient's best interests; whether the impact of treatment would significantly adversely affect the patient's quality of life to the degree where choosing conservative care would be in the patient's best interests; or whether treatment would maintain and promote a good quality of life.



**Examples:**

*Consultant 01: "I think it takes complex assessments, quite time consuming, with all the other parties, and then you make a decision about what you're gonna do, and often if it's a borderline case you're gonna have to try it and see what happens".*

*Consultant02: "...there's a big issue in terms of impact on quality of life and whether it's actually gonna be the right thing for them".*

*Consultant 02: "...the second big issue is their ability to actually tolerate or undergo or perform on one of the treatments"*

*Consultant 01: [of a patient] "...and we had long conversations about what to do, they [his family] were of the opinion as well, they were very much on board that there's no way this guy could dialyse, he just would never, I mean getting blood off him was really difficult...so you know we had a long discussion about whether we could think about haemodialysis which he clearly wouldn't do because he wouldn't want to be connected to a machine with blood flowing around for 3 hours, whether he could do peritoneal dialysis, whether they could do the dialysis for him but again they thought he'd just pull the tube out of his tummy. Then we talked about maybe just doing a pre-emptive transplant but they didn't think that was even a runner, and I have no doubts given the amount they had done for him that they were thinking in his best interests. And the GP agreed as well...So he went to conservative care".*

**Core Category 3: The Patient**

The consultants spoke of how the decision-making process and the management and coping of renal failure and treatments, were affected by a number of factors that were inherent and idiosyncratic for each patient; the patient's understanding, whether they had additional physical or psychological issues, and whether they had had previous experiences of ill health/health care.

**Subcategory 3a: Understanding**

**Description:** The category of the patient's understanding was an important one, and one that each consultant spoke extensively about. There was much discussion and several case examples cited in which a lack of understanding was either protective or detrimental for the patient. Sometimes having a lack of understanding was protective; it meant that some individuals did not worry about the current or future implications of being ill, such as having a reduced life-span, needing a transplant, or needing dialysis for the rest of their lives. Because the individuals were unaware of these factors, they

did not worry or feel anxious about them. Their lack of understanding effectively protected them from psychological distress. However, a lack of understanding also had the potential to become quickly detrimental and psychologically distressing. For example, one patient was initially psychologically protected by not understanding she needed a transplant (and what this would involve). However, when it became time to have a transplant she found herself in a scary, confusing and overwhelming situation. She didn't understand why she needed surgery, only that other people suddenly wanted her to have it and that it would be dangerous. In this situation, her lack of understanding had effectively left her psychologically unprepared for a major life changing event. Linked to understanding was the important factor of communication. The consultants often spoke about being careful in how they presented information and communicated with patients. The consultants also spoke of how a lack of understanding meant the patients often did not have the capacity to make treatment decisions, and were unable to give informed consent.

**Examples:**

*Consultant05: "perhaps learning difficulties, I don't want this to sound the wrong way, but you know protects them from processing a fear or thinking through the possibility of, you know, or asking questions that other people without learning difficulties might ask, will this affect my life span? I don't feel as if that is something they raise whereas sometimes I feel as if it's the elephant in the room with other patients without learning difficulties, and so perhaps in some ways it feels as if they are accepting of what happens in a way ..."*

*Consultant01: "people with learning difficulties seem to be more concerned with the short-term so the fact that their life expectancy has gone down from 30 to 15 years doesn't really impact on them..."*

*Consultant01: "perhaps some of the symptoms you get on dialysis might be quite hard to understand as someone with learning difficulties, you know like why you feel sick again, why you suddenly get cramp, and the fluids..."*

*Consultant03: "and I would say 'do you understand that if you stop [dialysis] you will die?', 'yeah', but he clearly didn't, you know? 'Is that ok? Do you want us to move you to palliation to keep you comfortable?', 'No!'. So we were stuck in this situation..."*

### ***Subcategory 3b: Additional physical/Psychological issues***

**Description:** Each consultant spoke of case examples where the patient also had additional physical or psychological issues, which affected the patient's ability to tolerate and cope with the treatments. A number of patients suffered from a needle phobia, which significantly impacted on the decisions made and the ability of the patient to manage dialysis (which involves the frequent use of needles). Other additional physical problems included spin bifida, cerebral palsy and other general mobility problems.

#### **Examples:**

*Consultant03: "...he's very scared of needles, every time we took a blood test he would be screaming like crazy..."*

*Consultant01: "he's profoundly deaf as well...he's registered blind and very deaf"*

### ***Subcategory 3c: Previous experiences***

**Description:** The consultants spoke of how the previous experiences of the patients of ill health or health care affected how they coped with the illness and treatments. These experiences were helpful if they had had positive experiences, or detrimental if their previous treatment had been distressing and this had become associated with medical interventions more broadly.

#### **Examples:**

*Consultant02: "he did have a traumatic experience when he was very young in hospital with needles..."*

*Consultant05: "and I think perhaps those other patients with learning disability that I've seen, many of them have had other special needs as well and so might have been used to having surgery...and somehow are accepting of that in the same way".*

### **Core Category 4: Support**

**Description:** Support was a significant factor, talked about extensively by every consultant. In the consultants' experiences, the patients who had supportive parents were more likely to cope and manage the transitions and treatments. Parents, families and carers played a significant role in the decision-making process and in providing emotional and practical support (for example, a number of parents managed home

peritoneal dialysis for their child). The consultants found that the patients who were more isolated were less likely to cope and therefore less likely to survive very long. On the other hand, the absence of more complex social relationships (like having a spouse or children) was thought to be a protective factor. The consultants felt that in comparison to patients who do have spouses and children, patients with a learning disability who don't have these more demanding relationships were protected by this as they did not have to worry about managing or maintaining them. For example, they did not have to worry about their family coping because they were no longer able to work and earn money. Further comments were made about friendships (both the lack of good friendships that were often noted about the learning disabled patients, but also about the supportive camaraderie that could be found on the dialysis unit), and the consultants and staff sometimes providing a supportive role for the patient. For the consultants, when the patients had invested and dedicated support (such as a parent) this meant that they could feel some of the responsibility for the choices being made for the person were shared, and the burden of responsibility upon the consultant lessened. Because of the presence of solid support, they felt more confident and less worried about the patient coping with the treatments (and the life changes that treatment brings). Conversely, it was more worrying for the consultants when the patients were less supported. Historically this has meant that the patient was likely to find it harder to cope.

**Examples:**

*Consultant04: "I think I can be definite about that, the two that I can think of who did really well effectively had single parents caring for them and that's what they did as their job, and the other two were in a more chaotic home circumstance".*

*Consultant02: "Certainly in my limited experience people who have supportive parents have a big impact, yeah in a variety of things in helping compliance with treatment, and understanding, and tolerance of treatment".*

*Consultant01: "I think one of the problems with the chap I'm thinking about who didn't do very well and died in the end is that he, he was on his own really. He did have a social worker, but there was no close family".*

*Consultant01: "I think loneliness runs through it...one of his sadnesses I think is he can't, cos that's why he asked about this deaf and blind group in Leeds, cos he would*

*love to have people other than mum and dad who love him, and sort of give unqualified love, he would love to have friends..."*

*Consultant01: "people who are in complex family or social relationships or whatever they are often a lot harder to make happy on dialysis because they, they can see where their body is you know, and their whole sort of mood and everything is, is falling apart much more...their happiness is probably a reflection of many more parameters than perhaps a person with learning difficulties is, so the fact they've got slashes all down their arms from fistulas, or the fact that they're impotent, or the fact that they always feel knackered whenever they see their kids and can't play with them, is probably going to affect them more, and it must be true isn't it that people who don't have learning difficulties are probably in more complex social relationships aren't they?"*

### **Core Category 5: The Consultant**

The consultants spoke about their responsibility and the intricacies of their role in treating patients with a learning disability. They spoke of their role in decision-making (as discussed above) where their belief as to whether a patient would be likely to cope with demands of treatment was a crucial factor. The consultants reflected on their awareness of their power and the influence that their position had, especially with regards to presenting information to family/carers. The consultants each spoke of having different levels of directness in their approach to treating patients and making decisions. Finally, they also spoke of the issues and difficulties around actually identifying the patients with a learning disability.

#### ***Subcategory 5a: Concern about identifying learning disability***

**Description:** Every consultant commented on the difficulties and intricacies of identifying learning disability within patients. They spoke of finding patients with severe (and therefore more 'obvious') learning disability more easy to identify and class as 'learning disabled'. Other patients who appeared as 'not quite right' and where the learning disability was not prominent would perhaps join the 'tricky group' of patients. One consultant expressed particular worry that there may be a third group of patients who have milder learning disabilities who attend the service, are quiet and acquiescent, but who might not fully understand what is happening. This consultant expressed concern that the service missing these individuals may mean they are not being supported properly. The consultants didn't only express concern about the

difficult identifying learning disability within patients; they also expressed concern about their ability to do so, and the possible ramifications of being unable to do so for the patients. This caused some worry and anxiety for the consultants. Each wished that they knew more about 'learning disability', exactly what it is and how to identify it.

**Examples:**

*Consultant04: "because we're not expert at that so we can easily miss that sort of thing I'm sure, and I guess I wouldn't know what the definition is, I mean I know we've got a number of patients who are illiterate...are they uneducated or is that a learning disability? I just don't know actually"*

*Consultant 05: "first of all, how good are we at detecting it when it's subtle? Or are we just expecting people to understand what we're talking about and treating them like we do the other 90% of the population. I think we must be very bad at that, I think we must be able to do that better, I think there must be a lot of people who actually don't understand what's going on but have just learnt to make it appear that they do, and I bet we're letting them down, I bet we could do them a lot better, that's one thing that's really stuck with me".*

**Subcategory 5b: Making decisions**

**Description:** As discussed above, the consultants played an important role in decision-making. The consultants spoke of making long and more complex assessments of the patient and their capacity for understanding information and the decisions, and discussed their presentation of the treatment options and their responsibility in making decisions.

**Examples:**

*Consultant02: "I think long extended explanations and attempts at different ways to give them some understanding is important..."*

*Consultant04: "we are all pretty aware of the fact that our treatments do have a significant burden on the patient and the need for them to engage with it in a pretty high order way..."*

*Consultant03: "...he was having a pretty tough life, quite a limited life...he can't tell us what to do, he does keep on saying he hates dialysis, I think we've reached the end here".*

### ***Subcategory 5c: Influence and directness***

**Description:** The consultants spoke of their awareness about the level of influence and power they had, especially regarding how they presented treatment options to the patient and their family/carers, and in the making of decisions. Some consultants spoke of their beliefs in treating patients with a learning disability regarding opting for treatment; one consultant felt that in general dialysis was not a viable option for patients with more severe learning disabilities, one spoke of having a try-it-and-see view, whilst another spoke of being unhappy if patients/families did not feel treatment was a viable option. The consultants also appeared to vary in the degree of directness employed in expressing their opinion on treatment options for patients with a learning disability.

#### **Examples:**

*Consultant04: "you know, so we have enormous power in the way that we, we present the treatment options, now if you present dialysis treatment as a veil of tears and a trial and hours and hours at hospital and horribly restrictive and you know treatment offers you less than 10% of normal kidney function at its very best and so forth, you're going to get a different response to if you present dialysis treatment as a life-saving option that's a holding manoeuvre until you can get someone a successful transplant, now I'm parodying the two extremes there but the response you get out of family or patients must be predicted by how you present it".*

*Consultant03: "Generally speaking you can kind of lead conversations in certain directions. So if you think that it's just a really bad idea to be doing dialysis you can normally carry people with you into that...but if it falls to me then I generally would lead people away from having dialysis treatment, it depends on how old they are of course, it depends on how much disability they've got as well, but for people who are very disabled I would normally take them down that [not having dialysis] direction".*

### **Core Category 6: Assessing Coping**

The consultants spoke about assessing coping; the difficulty defining the concept of 'coping', and the consultants' perception of not only how the patients coped, but how the consultants themselves and the wider service coped in treating patients with a learning disability. For the consultants, 'coping' was the patient managing the illness and treatments, without significant detriment to quality of life. The consultants spoke of assessing coping in two main ways: compliance (whether the patient attended and had dialysis, took medication, and restricted diet/fluids), and mood. This may perhaps

be divided into physical coping (assessed by compliance) and emotional coping (assessed by mood). The consultants' perception of how the patient was coping, and how the service may have coped treating the patient, influenced their treatment decision-making process and their treatment and management of the patient.

### ***Subcategory 6a: Defining Coping***

**Description:** Some of the consultants spoke about what was meant by coping, and factors that affected their assessment. They wondered from who's point of view coping was to be considered (the consultant or the patient), and discussed how coping and its evaluation could depend on the treatment type and the setting. For example, the consultants relied upon parent/carer feedback as to how the patient was coping with peritoneal dialysis as this occurs at home.

#### **Examples:**

*Consultant03: "not coping... it depends on what you mean by not going right of course, because that's not going right from our point of view for the long-term health of these individuals, from their point of view they may not see a problem with their phosphate being really high of course, they may be perfectly happy to roll up three times a week, have some dialysis then go home, eat whatever they want".*

*Consultant02: "it's difficult and it depends on where, the setting they might be in, maybe what sort of dialysis they're on...it will depend on the setting as well. If it's someone on haemodialysis shift in comparison to someone who is having PD at home whose carers are dealing with them..."*

### ***Subcategory 6b: Measuring coping by compliance and mood***

**Description:** Each consultant spoke of what they would look for when assessing whether a patient was coping with a treatment or not. They felt that compliance was the most important factor; whether the patient attended dialysis, restricted their diet and took their medication. A further important factor that the consultants spoke of regularly assessing and using as a coping indicator was that of the patient's mood (for example if they felt that a patient was depressed this was a sign of not coping).

#### **Examples:**

*Consultant02: "there may be symptoms, may be sort of mood or behavioural type things depending on their level of learning difficulty, may be compliance issues such as*



*the patient may refuse to go on, or wants to be taken off or refuses to agree to treatments”.*

*Consultant01: “...the other thing that must be important is their mood. So you want them in a good mood, and what they would score as a good quality of life for them...I think mood is important though. If they’re cheery and obviously assuming they’re not hiding a whole load of tears underneath, but if it’s a generally good mood then presumably you’re getting it right...in my experience, people with learning difficulties aren’t very good at hiding their mood. So if they, if they’re smiley and you know they tend to be fairly open don’t they, if they’re unhappy they look unhappy and act unhappy, if they’re happy they act happy, they don’t, they can’t act up happiness”.*

### **Subcategory 6c: Consultant**

**Description:** The consultants described how they coped treating patients with a learning disability. All the consultants spoke of this patient group being ‘trickier’ to treat; involving a greater input in time, assessment, thought and so on, but that despite this, working with these patients was rewarding. In comparison to other groups of ‘tricky’ patients (the elderly who often have a number of health complications, young patients who can sometimes be a bit ‘reckless’, and patients who have mental illness) a number of consultants felt that treating patients with a learning disability could often be easier and as a result preferable.

### **Examples:**

*Consultant05: “I think perhaps we all make an effort...I think all of us make an effort and are a little bit more aware, I think, we don’t just put him through like we might do with other patients in some ways, you know other routine patients who don’t have those special needs you know, perhaps just treating them a little bit specially, looking out for him, watching that it’s ok...everybody’s special and you make an effort with everybody and try and adapt to everybody but may be we’re all just slightly more aware of it and switch it on a bit more”.*

*Consultant01: “well they’re time consuming but I think that’s the only thing. I think most of them are a challenge and if you, when they work well they’re quite rewarding actually”.*

### **Subcategory 6d: Service**

**Description:** The consultants also spoke about how the renal service managed and coped with treating patients with a learning disability. Again it was felt that these patients involved greater work and more investment, but that the numbers of patients

with a learning disability in the service (that are known and require a greater level of input) were relatively small. In general, it was felt that the service coped well and provided a high level of care, although the decrease in staffing levels due to the current economic crisis was described as a significant concern. One consultant also expressed a concern that the service may be letting down patients with a milder learning disability by not identifying them and therefore not providing additional support. A number of consultants commented on how the environment, in particularly the ambience of the dialysis unit, and staff consistency could affect how a patient may cope with dialysis. If the unit atmosphere was warm, friendly and inviting this was likely to make the experience easier for the patient. The majority of the consultants felt that staff consistency was also better for the patients; they believed the patients found it easier and less scary when they knew the nurses well. However, as one consultant commented, this may quickly become detrimental if there was a staff member and patient who did not get on well, in regular contact. Some consultants have found that when the service used resources such as DVDs, looped televisions and reward systems, they helped patients to become familiar with what would happen, feel safe in the hospital, and encouraged the patient to allow the use of needles. However, one consultant expressed some concern that the service not only does not provide accessible information, but that the information leaflets they use are actually too difficult for the more 'normal' patient to understand.

**Examples:**

*Consultant02: "...they have more of an impact potentially, particularly if more time is needed around procedures, additional things need to be done, procedures they won't tolerate, or patients sort of being disruptive or non-compliant when attending dialysis, but in terms of numbers there's not a huge number or proportion".*

*Consultant03: "it really depends on the kind of vibe of the unit, cos we've got one of our big units that's quite a happy place actually and the people there, there is quite good banter between the staff, and banter between the patients and staff as well, so good place to be really...whereas another unit, very cold very clinical. When I walk on there I feel, it feels oppressive to me".*

*Consultant02: "he went home with one of those DVDs, that the patient used for education but I'm not sure he really understands it...he's actually been very happy to be*

*watching this process repeatedly on DVD and keeps playing it to himself actually so that's something that might sort of ease things when he comes onto dialysis".*

*Consultant03: "...and the way we did it was by giving him a sticker...we gave him a sticker every time he let us put a needle in his fistula and that worked...for the successful haemo patients the reward system was very effective when it finally occurred to us to do that".*

## **5.2 The Family/Carer Theoretical Diagram of Patient Coping**

Below is the theoretical diagram of coping derived from the family/carers data:

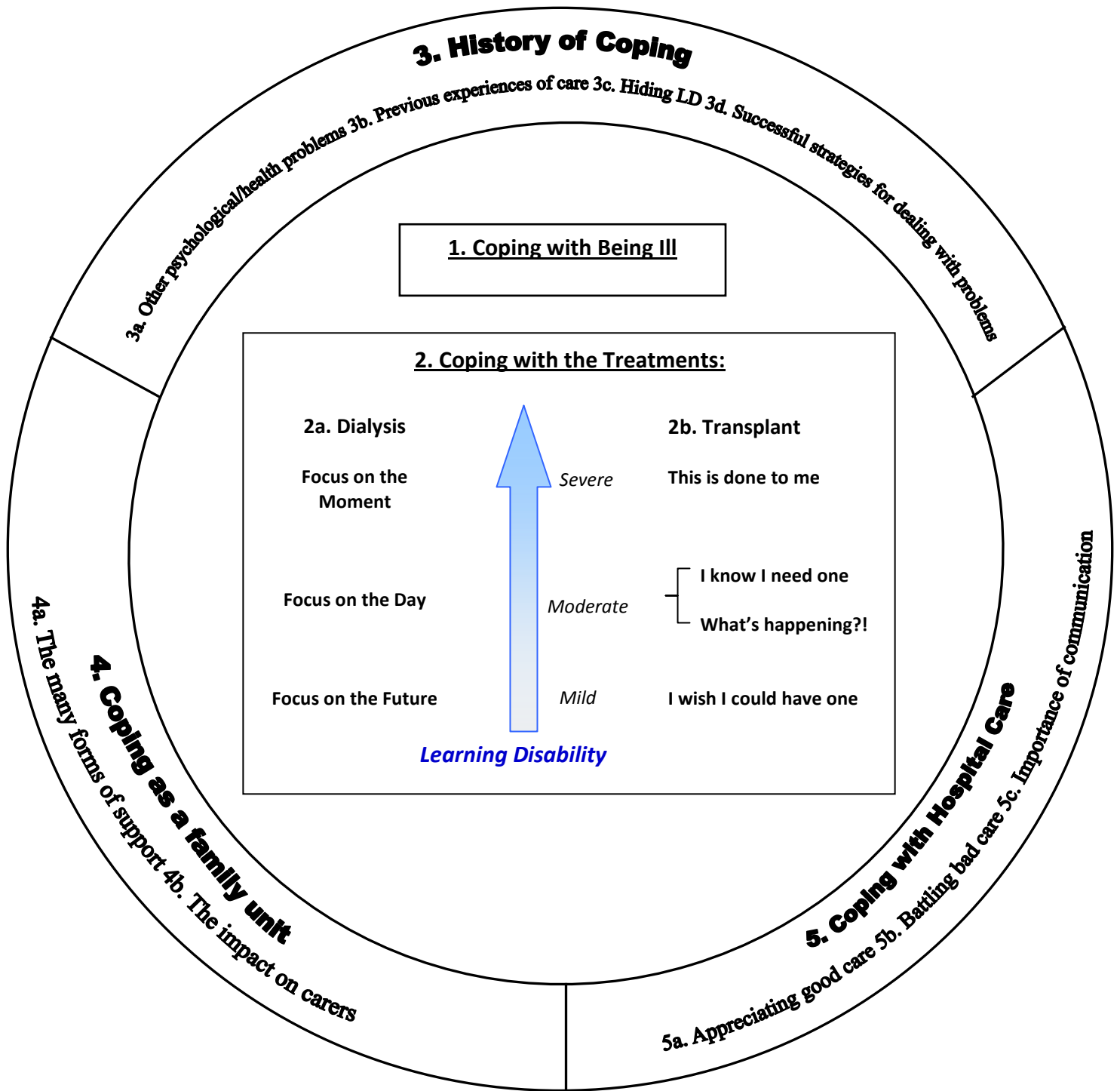


Figure 8. Theoretical Diagram of how Patients with a Learning Disability Cope with Kidney Disease - Derived from Family/Carer Data.

Central to the model (and represented as being so by being in the centre) was how the patient experienced and coped with being ill, how they coped with the treatments (dialysis and transplant), and how having a learning disability interacted and affected this. Encompassing how a patient with a learning disability managed kidney disease are three major categories;

- The individual's history of coping, including any additional health or psychological problems they may have had, their previous experiences of care, whether they hid their learning disability, and any successful strategies they had developed for dealing with problems.
- Coping as a family unit; the support that the individual had from their family or support workers was important. Support for someone with a learning disability with renal failure could be quite intensive, especially if a single parent/carer was providing it on their own. This could have an impact on the carers themselves.
- Coping with hospital care; good experiences, bad experiences, and how communication between the service and the patient and their family could affect their care experience and coping.

These three categories mutually influence each other, and how the patient managed and coped with the illness and treatments. Each core and subcategory is now discussed in more detail:

### **Core Category 1: Coping with being ill**

**Description:** Kidney failure can cause a number of initial symptoms. Symptoms described by the families/carers included itchiness, oedema (fluid retention), tiredness, collapsing and pain. They also spoke about how the dialysis can cause a number of physical side-effects including tiredness, nausea, and vomiting.

Complications, procedures and additional illnesses caused numerous physical affects ranging in severity; some of the most discussed was pain and generally feeling very unwell. The families found that in general, the more severe the physical affects the more difficult the patient found coping with them. For example, the more tired and nauseous a patient felt during and after dialysis, the more difficult and unpleasant they

found dialysis and the more they disliked going. However, it was also not always the case that the more severe the physical effect the more difficult the patient found coping with it. The coping of the physical consequences of the illness was affected by the other categories and by learning disability. One patient had a severe needle phobia and his learning disability meant he was not able to understand the necessity for their use. When staff try to use a needle he became distressed and would not let them use it. Whilst the pain of a needle is not the most severe, his lack of understanding and distress was so great that he found this difficult to cope with. Support also affected coping with the physical effects; for example one parent found that when his child was experiencing severe complications and was very unwell that his presence and support (someone the patient knew well and trusted) helped to soothe and calm him when the staff needed to perform procedures. Similarly the perception of staff as empathic could help when the patient was coping with feeling unwell.

**Examples:**

*Family05: "She was quite poorly afterwards and had quite a few setbacks, and spent a long time in hospital...It made her feel poorly and she didn't bother with how she looked and general appearance...yeah, she was very low. Because she didn't feel well you know, whereas before on dialysis she felt tired but she didn't feel ill. And now she's had this transplant, was supposed to feel ok, but was feeling really ill".*

*Family03: "Getting rid of the pain was a great help. Because he always said if he didn't have the pain he would be reborn. I was helping to dress and undress him at one stage, he couldn't bend or anything. Yeah he was in such pain with his back...he would be crying in pain, crying...And now the pain is, well it's eased, and that's so much better".*

**Core Category 2: Coping with the treatments**

**Description:** The families spoke a lot about the two main types of treatment – dialysis and transplant. One patient was about to begin haemodialysis. The other four patients all had or were still having haemodialysis. Only one patient had previously had peritoneal dialysis, which he had as well as haemodialysis. This meant that when the families were talking about dialysis they were talking about haemodialysis, and the category of 'dialysis' refers to haemodialysis and not peritoneal dialysis. The parents of the patient who was about to begin dialysis were just about to meet the transplant co-ordinator to discuss having a transplant. Two patients had had a transplant that had

been successfully accepted, and two patients were unable to have a transplant. For each treatment category the impact of having a learning disability on coping is discussed. The learning disability is in itself a core category, but one that intersects and interacts with the treatment categories.

### ***Subcategory 2a: Dialysis***

**Description:** The families all spoke of how difficult dialysis can be. There seemed to be an overwhelming theme of dialysis being a grind – the patients found it to be boring and often spoke of being fed-up. They had to go three times a week, and a number spoke about these days being very long (about 7-8 hours including transport time). The idea of three times a week, every week, forever (unless you have a transplant) made dialysis a never-ending grind.

#### **Examples:**

*Family03: “He’s not getting back till 7 O’clock. And it’s often late and I can see he’s upset...He just finds it a bore. Well it is you know, sitting and sitting for hours on end...He finds it boring, boring...He’s not coping very well at the moment, he’s had enough of it. It’s the life, very hard. You know, hours staring at nothing, three times a week. Monday, Wednesday, Friday. Very hard...It’s a grind. It really is a grind”.*

**Having a learning disability:** The families and carers spoke about how having a learning disability affected how the patient experienced and coped with dialysis. The patients with a more severe or profound learning disability focused on the moment; they did not understand what was happening (dialysis was something that was done to them) and they did not know that they would have dialysis again, although they may come to recognise the hospital and the dialysis procedure over time. If the patient had a severe needle phobia or endured unexpected painful procedures these patients expressed their distress with their behaviour, unable to understand or cope with what was happening. However, if they were supported they may have allowed procedures to continue. One parent spoke of his son (who has a severe learning disability) having respect for authority. He was not able to understand what was happening or why, but seemed to have a respect for strangers and hospitals and would comply and let them perform any procedure.

#### **Example:**

*Family01: "In some ways it's a good thing that he doesn't understand, that he doesn't have the worry. If I was facing dialysis and a kidney transplant I know I'd be worried and it's be at the back of your mind all the time, but to him...it's just out of his mind. He doesn't worry about it at all".*

*Family02: "I think you'd have to give him 10 out of 10 for everything, he just, he's very helpful with people in authority, he won't necessarily do what I want him to do, but if a doctor or nurse says something he'll do it".*

The patients who had a moderate learning disability focused on the day; the families spoke of the patient living day-to-day. They talked about the patient adapting and living in a dialysis routine. One patient seemed to appreciate the routine aspect of dialysis as it allowed her to feel that she was able to understand and manage the illness with some independence. The patients were aware that their kidneys did not work and that dialysis was necessary, however they did not have an awareness of the future or of the implications of the illness; for example, they did not know that they would have dialysis forever, or that their life expectancy had reduced. Because these patients focused on the short-term, followed the dialysis routine and did not worry about the serious or long-term implications, it was this group of patients with a learning disability that appeared to cope best with dialysis.

**Example:**

*Family05: "She just slotted into it. It was just something that to be better this is what I have to do. And I think she got herself quite organised, taking her packed lunch, and this is what I need to get ready, these are my dialysis days...I think she focused day to day. I think for her the gravity was if she went outside of her diet she could make herself ill. That was her focus. Because the words 'if you don't have a kidney in so many years', that's too far away. I'm dealing with this week, you know".*

The families of two patients who had a mild learning disability talked about how they struggled to cope with dialysis. They spoke of them struggling because they understood the long-term implications of kidney disease and focused on the future – they focused on the fact that they will need dialysis for the rest of their life and that it will never stop, never end. This focus on the future and awareness that he will always have dialysis particularly affected one patient's mood; his carer described him as feeling low and sad, and that he was not coping well.



**Example:**

*Family03: "And it's getting harder, not easier, because it's something he'll always have to do. Although the rest of the time he can do what he likes, it's always there either a day away or two days away...He says 'I've got this for life, and I'm struggling now after just a year', you know, and that struggle is making him depressed".*

**Subcategory 2b: Transplant**

**Description:** In general, for the patients who had some understanding that dialysis would continue unless they had a transplant, a transplant was hope. Hope that dialysis will finally stop and that a 'normal' life could resume. The families and carers of those who have had a transplant, spoke of how life resumed to what it was like pre-dialysis (once any complications had been overcome and the transplant had been accepted). The patients who were discussed in this research who had a transplant had had their transplant for a number of years. There had been complications immediately following the transplants which were difficult for the patients and their families to cope with, but these were overcome, the transplants successfully accepted, and the patients had lived without any further trouble or complication related to the transplant or kidney disease for the past 5-7 years.

**Examples:**

*Family03: "He talks about it [transplant], because he knows it's the only cure, the only answer".*

*Family02: "but if you can overcome your fears and all the rest of it, the transplant is without a doubt the best treatment for someone in my son's position, and at least following all these years and everything that's gone on between it I think I can agree with that now, my son's got a successful transplant and life is normal again".*

**Having a learning disability:** The families and carers spoke about how having a learning disability affected their understanding of having a transplant and waiting for one, and how the patient coped when they received it. The family of a patient who had a severe/profound learning disability described how their child did not understand anything about having a transplant or having to wait for one. The decision and wait had no impact on the patient as they had no awareness of it. When the time came for the transplant to happen, similarly to dialysis, the patient did not understand what was

happening or why; it was something that was done to him. It was this patient that was compliant and acquiesced to staff and procedures so he allowed the staff to anaesthetise him. Following the first transplant the patient experienced a number of serious complications and the kidney had to be removed. His father spoke of this being a difficult time. It was generally felt that his son struggled with these complications because of their nature – they were unplanned, serious, and caused pain and illness. His father felt that because he is generally compliant, his learning disability did not significantly impact on his coping whilst he was so ill. Now that he has a working and stable transplant, he was coping really well, with his father supporting him with his medication.

**Example:**

*Family02: "I mean you'd never believe you have to do it, you have no choice. And you have to coax him into sort of going into hospital and jolly him along, and then the anaesthetist comes and you're quite relieved when he's knocked out and they get on with it. You know, it wasn't such a bad experience which you obviously thought it might be but anyway it didn't work out too badly and he coped pretty well to be honest".*

One patient with a moderate learning disability had a transplant. Prior to the transplant the carer spoke about how this patient focused on the day-to-day routine of dialysis. She was aware that she needed a transplant, but did not understand what this actually meant or what was involved. When the time came and she was called in for a transplant, she became scared. She did not understand what was happening, and had found out she was going to have surgery and that this could be dangerous. She was afraid and expressed doubt that she wanted to go ahead. A carer arrived and went through the information (what was happening, why, and the possible consequences) a number of times. Her brother also spent a lot of time talking to her on the phone, trying to reassure her and to encourage her to have the transplant. She then changed her mind and had the transplant. Her lack of understanding about what a transplant is, what is involved in having it and the possible consequences was protective in the wait for the transplant as she had little awareness of it and it had little impact on her, however it became detrimental when the time came for the transplant to go ahead as her lack of understanding about what was happening meant it was confusing, scary and quite overwhelming for her.

**Example:**

*Family05: "I don't think the thought came into her head about a transplant, I think it was a word... I think she thought it was something that would never happen, I think she thought it was just a conversation. Because she could cope with the this is what is happening to me now".*

*Family05: "she needed to deal with the immediate, because it was the enormity of the situation that was happening to her there and then, she was going to have surgery and she was frightened...she spoke to her brother a lot on the phone and he was very much for it, go for it, do it you know, so that helped her I think.*

The family of two patients with a milder learning disability spoke of their son and nephew's disappointment that they were unable to have a transplant. One carer spoke of her son, who had not been definitively told that he could not have a transplant, who really wished for one. She described how he talked about asking the nurses about a transplant every time that he went for dialysis and that he was confused and disappointed that 'they haven't gotten back to him yet'. His carer believed that he would not have been put on the transplant list because he was in partial remission from cancer, but was afraid to ask for a definitive answer as she believed it would be a definite no and that the little hope her son had will disappear. The other carer described how her nephew was unable to have a transplant because the blood supply in one of his legs was not good enough. She talked about him being disappointed that he could not have one, because this meant he would never be free from dialysis. There were no patients described who had a mild learning disability who had a transplant so we cannot say how they coped when they received it. We can say however that both wished for a transplant and were unhappy that they were unable to have one, as they understood that this meant they would always need dialysis. We may therefore perhaps postulate that if they were offered a transplant, they would have coped well.

**Example:**

*Family03: "He's read about people who have had it [a transplant] and come off dialysis, and he always says 'oh I wish that was me. That should be me'...He's finding it harder. He dreads going to dialysis and he's got to do it for the rest of his life. And he just wants to go on the transplant list".*

**The other three Core Categories: History of coping, coping as a family unit, and coping with hospital care.**

**Description:** As previously noted, how the illness and treatments were coped with by the patient, were influenced by the patient's history of coping, their support and their experiences of hospital care. These three factors also influenced each other. For example, support influenced the person and the experience of care; if the patient had a supportive parent or carer, the carer may have helped their understanding by going through the information with them (as seen above when a patient did not understand what was happening when she was called in for a transplant). A supportive carer may have also helped them cope with hospital care by being with them in the hospital, aiding the staff or acting as an advocate for the person. Conversely, bad experiences of care could cause carer input to increase, as did the presence of additional illnesses or diagnoses that caused the patient increased hospital time and stress.

**Core category 3: The person.**

***Subcategory 3a: Other psychological/health problems***

**Description:** The families and carers spoke of some additional illnesses or psychological problems that their family member/service user had. It was generally felt that these additional diagnoses were detrimental and made coping more difficult. For example, one patient was diagnosed with cancer at the same time as he was diagnosed with renal failure and had to cope with starting chemotherapy at the same time as starting dialysis. He also had to cope with being in a lot of pain. Another patient had a severe needle phobia. He was visiting the dialysis unit once a week for up to two years in the work-up to him needing dialysis, with the staff trying to help him overcome his fear; which was unsuccessful. It remained to be seen how he would cope with haemodialysis.

**Examples:**

*Family01: "He's autistic as well, and has obsessive compulsive disorders".*

*Family03: " We know there's a lot of people who have kidney failure and he's not the only one, but you see he's got myeloma as well and these other people have just got kidney failure. Myeloma is a cancer of the bone marrow. And it's not curable".*

### **Subcategory 3b: Previous Experiences of care**

**Description:** Similarly to what the consultants depicted, the parents described how previous experiences of care (of residential care as well as health care) were detrimental or helpful for the patient when coping with renal failure. For example, the parents of the patient who had a severe needle phobia described how this was caused by a traumatic experience he had as a teenager when a number of nurses restrained him to take a blood test. Conversely, one carer spoke about how she believed the experience of living in care for one patient meant that she was used to living with routines, resulting in her then being able to adopt to and almost embrace the dialysis routine.

#### **Examples:**

*Family01: "he had a really bad experience, when he was thirteen they were looking to find out why he's got learning difficulties...so they wanted a blood test...so I took him to the phlebotomy, when he went she tied the tourniquet round his upper arm and she picked this huge needle and as soon as he saw it he sort of pulled away a bit and then she shouted at him 'keep still you stupid boy, how can I take blood if you're going to pull away?!', she went for him with it and he pulled away again and she got two male ward orderlies to hold him down but he pushed them off, he was only thirteen but he were strong you know, he just pushed them off and ran out".*

*Family05: "I mean you've got to remember that this is a young lady that's been in care the majority of her life, so is used to structured routines. Whether we have them now or not, if you have been, for want of a better word, in institutions since you were little your life is governed by routines. So falling into a routine was good, so if the routine of going to Jimmy's was Monday, Wednesday, Friday then that was ok".*

### **Subcategory 3c: Hiding LD**

**Description:** Important for one patient was how she hid her learning disability. Her carer talked about how she resented the diagnosis and did not like to think of herself as having a learning disability. Her carer described that because of this the individual had learned to appear as if she understood information; nodding her head and making noises of affirmation so that others would not realise that she has a learning disability. This sometimes affected her coping with decisions and the illness, for example she would acquiesce and agree to decisions without fully understanding what they meant. It also affected the other core categories, for example the communication between herself, her carers and the hospital was initially affected, and her care workers had to

work out how to provide the support she needed without affecting her sense of independence and control. Her carer did not discuss why she thought the individual hid her learning disability. It may be for a number of reasons, such as social desirability, disagreement with the diagnosis, or protection of her self-esteem.

**Examples:**

*Family05: "If you first meet her...there's a big assumption that she's very switched on and knows exactly where she's at. And she does. But her understanding of things is quite limited. But she makes the right noises, she can make the right facial expressions, and she can get by. If you go shopping with her she'll almost always pay with banknotes rather than try and use change because there's no understanding about how to use money. If you were to chat to her she could hold a conversation with you, but then if you sat with her for an hour you would have the same conversation again and again".*

**Subcategory 3d: Successful strategies for dealing with problems**

**Description:** Some of the carers talked about how the patients utilised previous coping strategies to help deal with the illness and treatments. For example, one patient was described as having a 'black and white' view, and a methodical approach to tackling problems. Her carer believed that this resulted in her tackling the restrictions in the same way; she was very methodical and exact in her approach. This good control of her restrictions meant that she experienced less side-effects from the dialysis, which made it easier for her to cope. Other examples were given such as using an emergency alarm system to call for help and dosette boxes to help take medication.

**Examples:**

*Family05: "I think some people are just black and white. And this is wrong and needs to be fixed, and she very much operates in this way. This is what you do, that's not ok, that makes it better, and that's how she is on a day to day basis with most things...she found out what was wrong with her and she was going to cope with it, and she was very methodical with how she did it...she coped admirably well to be honest and just got on with it. Just accepted it you know".*

*Family02: "he's respectful of people in authority. If you were to ask him to do something now he'd do it for you, he respects other people you know...He's marvellous like that and he put up with an awful lot, and he'd every right to think I've had enough of this you know and I'm not having anymore, but he didn't".*

#### **Core category 4: Coping as a family unit**

##### ***Subcategory 4a: The many forms of support***

**Description:** Each family and carer talked about the support they provided for their family member/service user. The family members were very close to whom they supported and their support was constant and intensive; together they would form a close unit. There was a wide variety of roles and types of support provided, such as emotional (providing comfort and support when they were in hospital), practical (supporting the person with dialysis, restrictions and medications, transporting them to and from hospital), and advocacy (for example, one parent argued with hospital staff and refused to let them move his son from the high dependency unit as he felt he was very ill, quite complex, and was worried that the move to a general ward would be detrimental for him). Interestingly, the families and carers all spoke of not playing a significant role in the decision-making processes regarding treatment; instead they relied on and followed the medical team's advice.

##### **Examples:**

*Family05: "To begin with she had staff support because she wanted someone to go with her. Then they would come back and relay the information. And go over it again and again and again with her until it would find a place where it would sit, you know, the parts she would understand".*

*Family02: "Me and his mum, you know, we've always given him 100%, doctors and nurses would say go home for heaven's sake you know, we haven't done that, we've sort of stuck with him and been there to sort of pamper him and look after his every need, if you've got children suffering, it's not fair to leave somebody like him on his own bewildered you know, on his own, so there's always been one of us around to help reassure, get a nurse or doctor, you know, you do whatever's necessary to get him through it...he has to have an advocate, somebody who cares for him and will look after him".*

*Family03: "Well I can't make any decisions because all the decisions come from the hospital".*

*Family02: "well you're into new territory, you don't know what's what, you've suddenly got your child in a life or death situation, what the hell do you do? I don't know, I have no knowledge of it...I'm quite content to have somebody give you that advice, somebody in the know...you're very much appreciative of somebody who steers you in the right direction".*

#### ***Subcategory 4b: The impact on carers***

**Description:** The families and carers all described how supporting someone with a learning disability and renal failure had some level of impact upon themselves. Those who were single carers and those who provided the most intensive support reported greater impact. For example, one mother (who was a single carer) talked about how she was unable to have a hernia treated and was unable to visit her daughter and grandchildren because she was unable to leave her son. A father spoke about how he or his wife would always be with his son when he was in hospital; which he was for a long time suffering from serious complications. Other carers spoke of feeling anxious and worrying about their family member a lot.

#### **Examples:**

*Family03: "I've got close friends who say you've got to look after yourself, they say I need a break, I need a holiday, I can't go. I need an operation, I can't go...I've still got a hernia cos I can't be spared. I can't have it seen to because I don't want to leave him...and I have a daughter down south and two small grandchildren. I would go and visit but I just can't do it cos I don't want to leave him...so I'm missing out there".*

*Family01: "It's just that now he's getting to this stage we're starting to worry more about where we go from here, what's going to happen. He doesn't understand or worry about it, but we do...we do all the worrying for him...it's at the back of us minds all of the time".*

### **Core category 5: Coping with hospital care**

#### ***Subcategory 5a: Appreciating good care***

**Description:** Every carer spoke of good experiences of hospital care and how this made a difference to the patient and their families' experiences and coping. The majority of the 'appreciating good care' comments focused around the hospital staff. The carers spoke of the staff being friendly, kind and understanding. They found it meant a lot to them when they thought that the staff had made an extra effort to support their child/service user. One family spoke of how the nurses would often give up their lunch break to try to help their son overcome his needle phobia. These examples indicate that the service may be trying to adapt care appropriately for these patients. Supportive friendly staff, and apparent extra efforts of care, were appreciated and found to make the time spent in hospital easier for the patient and their family.



**Examples:**

*Family02: "You don't want to be treated like everybody else, you want somebody to treat him as a special case and you know that's what you really want for him, a promise that they'll do their very best, and they'll look after him, because he's not a normal person and I think you need to be honest, I think you need an additional level of care...and on the whole I think 99% of our experiences are good, the staff they all do realise that he's a bit of a different case".*

*Family01: "they've been brilliant, couldn't fault them at all. They delivered everything they said they would and Dr X said I'll do my best to help and he has yeah...and the nurses gave up their time to try to get him to have a blood test and they did it during their own lunch breaks...so like really going to that extra effort putting more time in...and Dr X usually just rings me up, which is unusual for a consultant to ring you personally, I think he sees our son as a quest! [laughs]"*

*Family03: "And they're all, everybody's been very good you know, the care is wonderful, can't knock it".*

**Subcategory 5b: Battling bad experiences**

**Description:** A number of carers talked about bad care experiences that they and their family member had experienced, and also that they had witnessed happen to other patients. One effect of the bad care experiences meant that the family members felt unable to leave their child in the hospital on their own; someone needed to be with them all the time. The carers invested more time, worried more and felt more tired. Their family member benefitted from this in one way as they were constantly supported by someone they knew and loved. Of detriment was that they may have also sensed or realised that their carers and families were more tired and stressed. Bad care experiences had physical effects for some patients; during surgery a mistake was made causing internal damage to one patient. They also affected the relationship between the carers and the staff; being shouted at by a consultant caused damage to the relationship between the carer and that consultant. If the family member felt that the person they supported was at risk of or was actually receiving bad care, the family member would take on an advocacy role and battle the bad care on behalf of the patient. During an interview one family member expressed concern that they may be recognised though some of the information given throughout the interview. To protect

the families' internal confidentiality for this part of the results section the families will not be labelled.

**Examples:**

*Family: "I can remember turning up one morning, and you arrive there and he's completely messed, he's had an accident in bed, he's all messed up laying there and I'm thinking Oh God, anyway you start cleaning him up and sorting him out, and well I do it at home so it's not something alien to me, but you just hope you don't arrive in hospital to find that".*

*Family: "On the wards, I saw a guy there a renal patient, and he didn't look to be fully with it most of the time, and feeding him was very haphazard, the staff would bring him his meals and they'd be left in front of him...that left me thinking about what would happen to my child you see...so the same with helping with feeding, I'm not sure how big a help X would get, how much encouragement X would get without us there to do it...I wouldn't feel happy about leaving X on his own".*

*Family: "I wasn't impressed at some of the care level on that ward on there...a doctor wanted our son transferred to the LGI for dialysis and I remember my wife having a right ding dong with him, she refused to have him shifted down there because she felt he wasn't right. Ignorant I'd call him, he was just one of those doctors that, some have got a good bedside manner and some haven't, and in my opinion he falls on the bad one. And we were quite right because in no time at all our son was on his back, passing out and going for emergency surgery...We've got a good feel for things you know, and they might think that they know it all, but I can assure you they don't".*

*Family: "He went to Jimmy's first, he loved it there. And then he had to go to another dialysis unit [X] and he hated it. Then he moved to another unit [Y] where he is now and he hates it. It was the staff you see they were funny with him [at unit X], it turns him off. There was a nasty nurse there. Then when he thought he was moving to a brand new unit [Y] he was excited, thought it would be new, with new staff. But most of the staff at the first unit [X] followed him there! He kept on wanting to go back to Jimmy's. But he never did so he has to put up with it".*

**Subcategory 5c: Importance of communication**

**Description:** Some of the families and carers talked about the importance of the communication between the hospital staff and the carers/patients. Good and bad examples were given. For example, communication was initially difficult with the patient who showed compliance so that others did not realise she had a learning disability. Her carers were unaware of what was happening at the hospital. When they realised what was happening, the hospital began to communicate with the care home and the carer described that they had a good relationship; the hospital effectively kept

the balance between informing the care home of information they needed whilst continuing to support the patient's desire to be independent and in control. Bad examples were also given regarding communication, such as the patient and carer who were in a state of uncertainty and anxiety regarding his wish for a transplant. She described him as being confused, worried and upset that no one had told him he could or could not be on the transplant list, whilst his carer was afraid to ask as she believed the answer would be 'no'.

**Examples:**

*Family02: "They frightened us to death. When we came in the morning after the transplant his bed wasn't there and two consultants came in and said 'we've got some bad news' and I thought he'd died! But the news was the transplant failure".*

*Family05: "She would tell us but it would be her level of understanding of dialysis, and so then we would speak to the hospital staff and they would tell us if there was something we needed to know"*

*Family03: "But nobody's said anything, and he says 'I can't understand it, they haven't gotten back to me and I'm always pushing them about it'...but I don't want to say anything in case we don't like the answer...but I don't want, he might say no and I don't want him to know that. He has to have some hope".*

## 6.0 Discussion

The discussion begins with a summary of the results. It describes the differences and similarities found between the two models. The findings are related back to the literature, and a number of clinical implications are presented. The discussion finishes with thoughts about the strengths and limitations of this study, and ideas for further research.

## 6.1 Summary of Results

The purpose of this study was to add to the small but important literature base on how people with a learning disability cope with a chronic illness. More specifically, the study aimed to use grounded theory analysis to produce two theoretical models of how patients with a learning disability cope with kidney disease and its treatments, derived from the data provided by interviewing five consultants and five family members/carers.

### *6.1.1 Research Question 1: How do consultants perceive patients with a learning disability cope with stage V kidney disease and its treatments?*

The first research question focused upon the consultants' reflections on how well their patients with a learning disability cope. Part of this research question was also to enquire as to how the consultants themselves and the service in general cope with treating patients with a learning disability. A particular strength of this study is the wealth of data the consultants supplied; they did not just focus on the medical aspect of the illness, but spent significant time discussing other aspects of their patients' experience of kidney failure, including the psychological, emotional, environmental, and their available support. The main findings were:

- 1) There was a possible contextual element: one consultant feared there was a possibility of a referral bias - that GPs and other healthcare professionals were not referring patients with a learning disability to the service, perhaps because they believed the treatments would be too difficult, or perhaps because they believed the service would not treat them.
- 2) The consultants spoke of the disease management as having two significant themes:
  - The stages of the disease and the growing demands placed upon the patient: from stability, to transition, through to complications (which had the highest demand). The patients appeared to cope best when they were in a period of stability, for example when the transplant had been accepted and normal life

had resumed. Fast transitions (such as starting and stopping dialysis) were found to be more difficult to cope with as new and potentially frightening things were happening to the patient that they were uncertain about, did not understand the necessity for, and that could be painful and caused side-effects. Complications, especially severe ones that required extended stays in hospital and painful procedures were found to be the most difficult to cope with. It felt that this level of difficulty was due to the inherent nature of complications; they were unplanned, severe, painful and distressing. The consultants did not talk about learning disability affecting coping at this stage.

- Decision-making: the consultants talked a lot about decision-making. There were a number of important life-changing decisions to be made and an ongoing decision-making process as to whether the current treatments were appropriate for the patient. The consultants spoke of having increased responsibility, making decisions on behalf of these patients. They also spoke of the importance that the families and carers had in their support or disagreement with their choices. Finally, the consultants spoke of the intricacies of the decision-making process which culminated around trying to predict whether the patient would be able to cope with the treatment so that the impact of it would not significantly detract from their quality of life – i.e. would their life be better or worse with dialysis?

3) The management and coping of the disease and its treatments were affected by four major factors:

- The patient – coping could be affected by a number of factors that were central and unique to the individual patient; their understanding, any other physical or psychological issues (such as needle phobia), and their previous experiences.
- Support – a patient was more likely to cope if they had dedicated and invested support, such as a parent or family member. Some paid carers had also been found to be helpful. The patients without support, who were more isolated, were found to be less likely to cope. The consultants found that people with a learning disability were less likely to have friends, making other forms of support (such as family) even more important. Conversely, the consultants also

believed that the lack of other complex relationships that tended to make demands from an individual (such as marriage or parenthood) was a protective factor.

- The consultant – the consultants spoke openly about a number of their roles (such as decision-maker), and their awareness of their expertise and power, all of which influenced decision-making and coping. Of import was the difficulty and complexity of identifying which patients had a learning disability, which all consultants expressed concern about. Whilst the consultants were aware of their power, especially in the way they presented treatment options to the families, they differed in their view and degree of directness in their approach.
- Assessing Coping – Finally, linked to the factor of ‘the consultant’, was the consultants’ assessment of coping. The consultants viewed and assessed coping in two main ways: compliance and mood. If the patient regularly attended appointments, dialysis, and took their medication, and did not express distress or significant low mood, this equated to coping. There were some factors that could affect how they assessed the coping such as the type of dialysis (for example peritoneal dialysis occurs at home so the consultants relied on the family/carer’s feedback as to how the patient was faring). The consultants spoke of how they believed they and the service coped. For the consultants, they found that treating patients with a learning disability could be more time-consuming and complex, but that actually the patients could be quite rewarding, and noted that some other groups of patients were no less ‘tricky’. They have also found that in general the service coped well, but that the staff and unit ambience could (either positively or negatively) affect this. One particular concern that arose was the possibility that there may be patients with a borderline or mild learning disability that the consultants may not be identifying, who may be acquiescing with what is suggested without fully understanding the information, and therefore not receiving the support they need.

From the consultants' point of view, coping with renal failure in patients with a learning disability consisted of making decisions and managing the disease at various stages with varying levels of demand being placed upon the patient. Managing and coping with the disease could be supported or detrimentally affected by a number of factors that were unique to the individual (such as their understanding), their support and the types of relationships that they did or did not have, and by the consultant themselves.

*6.1.2 Research Question 2: How do families and carers perceive their family member has coped with stage V kidney disease and its treatments?*

The second research question focused upon family and carer views of how their family member coped with kidney disease and treatments (including how they felt they coped with the onset and diagnosis, decision-making, illness symptoms, and treatments). The main findings of the study and the model produced suggest the following:

1) Coping with the symptoms of the illness and side-effects of the treatments: the carers found that generally the more severe the physical symptoms and physical consequences of treatments, the more difficult the patient found coping with them. However, this was not always the case. The level of distress experienced because of physical symptoms and how this was managed was affected by factors associated with what the individual person brought (their understanding, previous experiences etc), their support, and their experiences of hospital care (including having to cope with bad care, appreciating good and enhanced care, and the importance of the communication between the renal service and the patient and their support).

2) Coping with the treatments: the research found that for these carers and their family members with kidney disease, the group of patients who appeared to cope best with the demands of dialysis were those with a moderate learning disability. These patients appeared to adapt well to the routine of dialysis - it was felt that they were not aware of the serious and long-term complications of the illness and therefore did not worry about them. This lack of understanding also seemed to protect them with

regards to waiting for a transplant; they did not appear to understand what may or may not happen when having a transplant, and therefore the possible operation and the wait for it did not impact on them. However this lack of understanding became detrimental when the transplant occurred, as it was a scary, confusing experience for which they were unprepared. For patients with a more severe or profound learning disability, again they appeared to be protected by not understanding and not worrying about the illness or its implications. If they were able to allow procedures (like the patient who was described as being compliant for people in authority) they appeared to cope well with dialysis. However, if needles or other procedures caused distress, this could be expressed through behaviour that the medical team found challenging and thus prevented the procedure from going ahead; the patient therefore did not cope so well. The patients with a mild learning disability appeared to struggle to cope the most, this was because they understood the full long-term implications of the illness and the consequences of not being allowed a transplant; they would have dialysis for the rest of their lives.

3) Other factors influencing coping: Surrounding the patient and encompassing their coping experiences were three major factors:

- History of coping – these were factors that were central and unique to the individual, including coping with any additional illnesses or diagnoses they had (these were generally found to make coping more difficult), their previous experiences of healthcare (such as procedural distress around needles), whether they hid their learning disability, and if they had developed any successful strategies for coping with problems.
- Coping as a family unit - in general having support significantly aided coping, and this support came in many forms. However, supporting someone with a learning disability to cope with stage V kidney disease could also have an impact on the carer, especially if they were a single carer providing an intensive level of support on their own.
- Coping with hospital care – The experience of hospital care, good experiences and bad experiences, also affected how well the patient coped. In general, if



the staff were warm, friendly and supportive, this aided the patient and their coping. The same is true for the opposite if bad care had been experienced. These factors also influenced and affected each other.

In summary, the level of learning disability affected how the patients understood and coped with the treatments but this was a complex relationship. A lack of understanding about the future and implications was believed to be protective, and a level of ability that allowed the patient to partake and manage the new routines of dialysis life was also found to be helpful. The person and their history of coping, the level of support they have access to (and the support that their support has), and the level of care that the hospital is providing should all be assessed when thinking about coping in patients with a learning disability.

It is important to note again that the reflexive position of the researcher (a trainee clinical psychologist wishing to explore how people with a learning disability may cope with renal failure) will have interacted with and shaped the analysis and models produced. For example, the researcher's training in clinical psychology is likely to have meant that her questioning technique was curious and non-judgemental, perhaps allowing the participants to feel safe enough to discuss their own feelings and experiences in more depth. This has resulted in the researcher obtaining information (such as the impact upon carers, the level of responsibility felt by consultants and so on) that has been incorporated into the models. Awareness of the reflexive position of the researcher in relation to the results and conclusions is therefore important.

### *6.1.3 Considering Synthesis*

Significant thought was given to the possibility of attempting to synthesise the two models into one model, but it was decided not to do this. A strength of this study is the wealth and depth of information gained from both the consultants and families. These two pools of data have been used to generate two models of coping, both of which

describe interesting and important aspects of how patients with a learning disability may cope with illness. The two groups and models focus on different aspects of coping. The consultants' model has more of a focus on process, and they were able to think about the complete journeys of a number of patients. They spoke from the point of view of having to hold a significant amount of responsibility for decision-making and treatment. The carers focused more upon the practical aspects of coping with the illness on a day to day basis, for the individual and for themselves. There was a stronger feeling of their accounts being grounded within the illness experience. It was decided that trying to force the models into one would result in losing some of the differing and important features of each model; in short, we would lose more than we would gain in trying to merge them together. The models represent two separate views regarding one central process, each with differing foci, and should be treated as such. Each group has their own perspective, both of which are equally valid. Although the research focused upon the participants' understanding of the experiences of people with learning disabilities, insights into the participants' own positions and experiences, and how they make sense of the patient experience through these, were discovered. Keeping the models separate has allowed reflection of the implications for, needs of, and contributions made to patient care by both groups. Forcing synthesis would result in losing these implications and producing a model that is more artificial in nature.

Additionally, grounded theory was the chosen method of analysis as it allows theory to emerge from the data, rather than trying to make data fit into predetermined categories or ideas. To try to put the two models together may detract from this central idea; two theories have emerged from and are grounded in the data – perhaps forcing them together is in itself trying to fit a predetermined idea that producing one model is the ultimate goal. In summary, the two models provide differing perspectives and information as to how individuals with a learning disability may cope with end stage renal failure. Attempting synthesis would likely result in the loss of some of the differing aspects and focus. However, as the two participant groups were discussing a common subject (how people with a learning disability cope with kidney disease), it is

important to reflect upon any commonalities and potential contrasts between the accounts. Similarities and differences between the models are therefore discussed in depth in the next section.

#### *6.1.4 Similarities and Differences between the Two Models*

A number of similarities and differences between the two models have been noted. Both models commented upon the importance of the patient's support; both the consultants and families/carers recognised that having consistent and invested support (such as a parent) helped the patient to cope in a number of ways, by providing emotional and practical support, and also by being an advocate. The consultants spoke about having and not having other different types of relationships, noting that in their experience patients with a learning disability are less likely to have friendships, partners and children, and were instead more likely to rely upon family members or support workers for support.

The issue of identifying learning disability came up in both the models. The consultants spoke of the complexity and difficulty there was in identifying patients with a learning disability, and voiced a concern that there may be a number of patients who have a mild learning disability who may be complying without fully understanding what is happening. Interestingly, the family/carers model includes the category 'hiding learning disability', following the description of how a woman with a moderate learning disability disliked being known as having a learning disability. She made great effort to 'fit in' and to not draw attention to the fact she had difficulty understanding. This resulted in her initially complying and agreeing with the renal team despite not understanding what was happening, until the hospital and her support staff realised this was happening and began communicating with each other. When contemplating coping in patients with a learning disability, how patients with a mild learning disability are identified and how the patient perceives their learning disability are important factors. This becomes more important when we consider that the group of patients

who appeared to struggle the most were the patients with a mild learning disability on dialysis (and who were unable to have a transplant). These patients appeared to struggle more because they had some understanding that they would need dialysis for the rest of their lives and were more likely to be socially isolated (they were less likely to have friends and partners). Therefore it is important that the service is able to identify these patients to make sure a) they understand what is happening, b) that they have enough support, and c) that they are coping if they have been given bad news such as not being able to have a transplant.

Both models appreciated the importance of the patient's understanding, their previous experiences and if there were additional diagnoses or illnesses that the patient had to cope with.

The consultants spoke of the potential of patients with a learning disability to become 'great' or compliant patients because they 'just get the routine'. This observation was supported with the story of a patient described by her support worker. Her support worker believed that because she had spent the majority of her life in care, her life so far had been governed by routines. So when dialysis began, she adapted to the routine well and was methodical in monitoring her restrictions and taking her medication. Other families and carers talked about how good their family member/service user was with their medication routine.

However, there are some differences between the models. For example, in contrast to the consultant's model, the carer's model was more descriptive and practical with less focus on process. The consultants were in a position where they were able to reflect upon a number of patients and their experiences, and to reflect on the whole journey of coping with renal failure. There is a sense that the families' accounts were grounded in their being within the experience itself. There are a number of reasons as to why their model may be more practical with less focus on process:

1. It reflects the difficulty there can be in trying to understand and talk about someone else's experiences.

2. It may be that supporting and looking after their family member all of their life, perhaps through a number of trials and difficulties, may mean that the renal failure is almost 'just another hurdle' and is so approached in a practical manner, with less focus on process.
3. It may reflect some underlying assumptions that there may not be processes occurring for the patient because of their learning disability.

The consultant's diagram highlighted the importance of the consultant and their assessment of coping. The family/carers diagram did not make a specific issue of the consultants' role, rather they were more concerned with the broader experience of hospital care (whether it be good or bad) and the effect that this had on the patient's experiences and coping. Whilst both groups discussed the importance of support, the carers highlighted the personal impact of caring for someone with a learning disability and stage V kidney disease.

The consultants highlighted how important they felt decision-making was in managing the illness. Interestingly, decision-making was rarely mentioned by the families and carers. What little was said was that the family or carers did not really play a role in decision-making; the renal team would make recommendations and they would simply follow them. One family member spoke of this being reassuring, declaring that at the time he had little knowledge and experience of renal failure, and was happy to have an expert point them in the right direction. However, the exception to this appeared to be if the families perceived that what the hospital wanted constituted bad care or was possibly detrimental for their family member (such as moving a patient from high dependency to a general ward). If this should occur the carer would take on an advocacy role and almost 'fight' on behalf of what they felt was best for their family member.

### *6.1.5 Concluding Comments of the Results*

The ability to cope appeared to have a complicated relationship with the level of learning disability. The results of this research showed that of the three levels of learning disability (mild, moderate and severe) it was those with moderate learning disability who seemed to cope best with dialysis over a long period because they were not aware of the seriousness of the situation whilst still maintaining sufficient ability and capacity to cooperate with the routines. However, if they were immersed in the transplant situation they could become confused and frightened. Patients with a mild learning disability however were not protected by ignorance of the seriousness of the situation, and suffered high levels of stress which their learning disability made them vulnerable to. They realised that a transplant was an alternative to permanent dialysis, and if confronted with the transplant situation would have been likely to do well. People with severe learning disability did not seem to realise the gravity of the situation with regard to dialysis, but if compliant would allow things to be done to them and enabled the procedure to go ahead. There was however a possibility they would respond to interventions with distress expressed through their behaviour, which could then prevent dialysis from taking place.

Both models agreed that the patient's previous experiences, additional diagnoses, their available support and type of support, and their experience of hospital care (including the role of the consultant) were all important factors that could aid or hinder the patient's coping.

## **6.2 Integration of the Study Findings with the Current Literature**

The earlier literature search first focused upon the definition of learning disability and chronic illness, and it reviewed some papers discussing inequality in healthcare for people with a learning disability. It then went on to discuss a number of psychological

models of coping and adjustment to illness. The results are now integrated with some of the literature that was reviewed.

### *6.2.1 Definition of Learning Disability*

It was reflected when discussing the definition of learning disability that there are on-going issues regarding the idea and label of 'learning disability'; its use and viability as a diagnostic term, and how people with a learning disability feel about it as a label. These issues were aptly demonstrated in the study by a carer describing how their service user disliked having a learning disability and others knowing that she had one, and went to great effort to ensure her learning disability was hidden. This finding corresponds to some literature developed regarding how people with a learning disability can feel about the diagnosis and the efforts they may make to hide it. For example, in 1967 Edgerton published a famous book entitled 'The Cloak of Competence; Stigma in the Lives of the Mentally Retarded'. In this book Edgerton studied the everyday lives of a number of individuals with a mild learning disability adjusting to community life after being discharged from institutions. He found a significant level of stigma directed towards and experienced by the individuals, and described in detail how the individuals went to great lengths to hide their learning disability. They denied their learning disability in order to try to be and feel 'normal' in society. This denial was termed the 'cloak of competence' by Edgerton.

The issues around learning disability as a diagnosis were also reflected in the consultants' concerns about how they identified patients with a learning disability. As one consultant queried:

*Consultant 05: "I know a lot about dialysis and kidney failure, I don't know a lot about the definition at all of learning disability, I feel as if I sort of perhaps know kind of what you're driving at but that's about it, I don't know an actual definition. You know it must be different from just what your IQ is but just what is the difference? I don't know".*

### *6.2.2 Definition of Chronic Illness*

The literature review looked at chronic illness and discussed the implementation of the DoH's stepped care model of managing chronic illness (2005) which aims for the care of patients with long-term conditions to be planned and personalised instead of reactive and episodic. There was evidence of the renal service planning and personalising the management of renal disease for some patients with a learning disability; for the patient with a severe needle phobia a number of strategies were employed over a number of years in preparation for him starting haemodialysis. There were also plans for him to start the dialysis earlier than necessary so that he did not have to get used to the dialysis when he desperately needed it. There was also evidence of some of the care being reactive and episodic, for transplants and inpatient stays. Planning for transplant might be more difficult as there is no certainty that the patient may have one, if so it may be many years away. It may be that an initial plan with regular reviews may be helpful in aiding the patients' understanding so that when the time for the transplant came it may not be as confusing and overwhelming.

### *6.2.3 Learning Disability and Healthcare Legislation*

The literature review discussed a number of publications that described inequality in healthcare for patients with a learning disability. Examples of good and bad care were described by the participants in this study. A number of carers described feeling that their family member received more attention and support from the service, and were treated almost like a 'special case'. Such enhanced care follows the guidelines and recommendations made by a number of the reports reviewed, such as Valuing People (2001). However, there were also examples of bad care (such as the patient being left in bed needing personal hygiene). It is unclear whether these episodes of bad care are related to the person having a learning disability, they may in fact be more related to being a patient that is more dependent and complex to care for (if this is the case, a number of other patient groups may also fit this category). This research did however,



highlight the difficulties and complexities inherent in decision-making about treatment, with the consequences causing upheaval, drastic changes in life, and requiring a high level of engagement and compliance. For example one consultant discussed a distressing case where a patient with a learning disability found dialysis very distressing and would often cry and talk about how much he hated it and did not want to go. However, he also did not want to begin palliative care; he did not understand why he could not stop dialysis and live. The consultant spoke of how he and the service felt like they were almost 'torturing' this patient, feeling stuck and unable to find a solution. There was a further concern discussed by one consultant that in his view the service should probably have treated more patients with a learning disability than they have, leading him to question if there was a referral bias; that for some reason patients with a learning disability were not being referred to their service.

#### *6.2.4 Definition of Coping*

The literature review presented a definition of coping. Folkman and Lazarus (1986) define coping as:

“The person’s constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the person’s resources” (p993).

The above definition has a focus on the individual’s cognitive efforts. However this research has seen that a lack of awareness and understanding could be protective and in fact aid coping, especially with regards to reducing the possibility of anxiety, worry and preoccupation about the future and implications of the illness. We have also seen how the patients used their behaviour to express their distress. As the degree of learning disability increased there was less potential for the individual’s cognitive efforts to change, adapt and to be helpful. There may therefore be an increased reliance upon behavioural efforts. However what is not present in this definition is how the presence and input of others, and the environment itself, can play important roles in how patients with a learning disability may cope.

It is interesting to note the difference between this definition of coping (the individual's cognitive and behavioural efforts) and how the consultants defined coping. The consultants measured and viewed coping as compliance (that the patient came to dialysis) and mood (whether the patient appeared to be happy or sad/distressed). Their view was less about the individual's efforts and more about the use of two visual indicators which were more readily available to the consultants. This raises further interesting questions such as how reliable is mood as a measure of coping? Is it not possible to feel sad but be coping well? It is evident that there can be significant variety in how people construct their ideas and beliefs around what constitutes coping.

#### *6.2.5 Psychological Models of Coping and Adjustment to Illness*

The literature review identified psychological models of coping and adjustment to illness, with questions and ideas raised about how the presence of a learning disability may affect how each may work. Unfortunately it is beyond the scope of this project to re-review each model again to relate it to the results. However, the results of this research have shown that the presence of a learning disability did affect coping, and it is very likely that these models would be affected by learning disability. Some instances of how this may be are now given. For example, Taylor (1983) proposed a theory of adaptation to threatening events consisting of three processes; a search for meaning, a search for mastery and a process of self-enhancement (increasing self-esteem). Questions were raised in Chapter 2 as to how having a learning disability may affect the ability to search for meaning. The present study found that even for the patients with a milder learning disability this task was taken on by their support and family, who would attend appointments, ask questions, and gather and sort through information. A sense for mastery may also be affected. The patients discussed in this study who had a more severe learning disability or other conditions such as cerebral palsy were less able to achieve mastery over the illness; procedures and treatments were done to them. Individuals who do not have a learning disability are more likely to have the capacity to decide and consent to treatments and procedures. Patients with a

learning disability, especially a more severe learning disability, are less likely to have this capacity. As a result, for these patients with a more severe learning disability, procedures were often done to them. For example, one patient described in this study with a severe learning disability and cerebral palsy was unable to undertake any aspects of the disease and treatment management, or his own personal care, by himself. He relied completely on his parents and support workers to carry out all tasks. Another patient with a mild to moderate learning disability struggled to understand the dietary requirements and fluid measurements and so relied on his family to work these out and monitor them for him. However, one patient found that the routine of dialysis and managing the restrictions gave her a sense of mastery as she was able to know what was going to happen when, and follow the routine. Interestingly, self-esteem was not explicitly discussed by the consultants or the families, except by the support worker who actually described how their service user was proud that she had coped with dialysis and a transplant; she spoke about it often, and her fistula was seen as a badge symbolising what she has been through. It appears that perhaps the management of the disease through to the successful acceptance of a transplant can, for some, enhance self-esteem. Conversely, the patients with a milder learning disability who were unable to have a transplant essentially had to have dialysis for the rest of their lives if they wanted to live. This may have removed a sense of control from the person (they were dependent upon the hospital and dialysis to live), which possibly affected their self-esteem.

Perhaps the most influential model of coping is that of Folkman and Lazarus (1986). They propose that the interpretation and perception of how stressful an event is, is more important than the event itself. The current research found that a lack of understanding about the future and implications of the illness could be protective as the patient did not worry about it. They did not interpret it as stressful and they therefore did not find it stressful. Patients with a more severe learning disability may not have had the cognitive capability to interpret their perceptions about stress. In their case it may be that the event itself (for example a fistula being blown by a needle causing pain in the arm, significant bruising, and an inability to move the arm) was

more distressing than their interpretation of it (as they were unable to interpret what has happened). Folkman and Lazarus also introduced the ideas of problem-focused and emotion-focused coping. There were examples seen of problem-focused coping; the lady who methodically managed her restrictions, writing everything down in a book. There were also signs of emotion-focused coping in patients who refused in some ways to comply with the restrictions; small acts of rebellion (such as refusing to stop drinking fizzy drinks, refusing to stop eating some favourite but 'banned' foods, or refusing to take some large tablets) were carried out to achieve some sense of control and to combat feelings of anger and hopelessness.

The final model to be deliberated is that of Moos and Schaefer's 'Model of the Coping Process' (1984). They propose that individuals utilise coping strategies in order to complete a number of tasks; tasks relating to the illness or treatment, and tasks related to general psychological functioning. They suggested a number of coping strategies that might be employed. The results of the current study suggest that these strategies may be affected by having a learning disability:

- Denying or minimising the seriousness of the situation: depending on the level of the learning disability, the individual may not understand the implications of the illness. This may be similar in effect to denial as they do not feel anxious or overwhelmed.
- Seeking information: This research found that the seeking out of information was a task taken on by the patient's family and carers.
- Learning to provide one's own medical care – the patients described in this study were unable to provide their own medical care. For example, peritoneal dialysis was only offered if there was enough support at home and another person who would be responsible for administering the dialysis. Most of the families/carers supported their family member or service user (to some level) in their medication use and restriction, although a number of the patients made efforts to manage their own medication and restrictions.
- Setting concrete, limited goals: This strategy was utilised by some patients, for example by focusing on managing and measuring the restrictions and medications, and completing the tasks set for treating needle phobia.

- Recruiting instrumental and emotional support: the results from both the consultant and family carer data sets describe how important support is for patients with a learning disability. If the support is not there to begin with, the person with a learning disability may be unable to find and recruit new support by themselves.
- Considering possible future events: this strategy depended on the individual's level of disability and their understanding. Those with a more severe learning disability were unable to think about and prepare for future events; this could be either protective or detrimental. Patients with a mild learning disability struggled to cope when they learned and realised the implications of not being allowed to have a transplant.
- Gaining a manageable perspective: patients with a learning disability are less likely to find a long-term 'purpose' and 'meaning' for the illness as they are less likely to have the cognitive ability to develop these quite abstract concepts.

In summary, the literature review highlighted some issues regarding the definition of learning disability and chronic illness, and similar themes were discovered in the results. The results also provided possible examples of how the renal service was trying to personalise and plan the management of renal failure, although at times the care could be episodic or reactive. The literature review discussed a wide range of psychological models of coping and adjustment to illness, none of which incorporated the possible impact of learning disability. The results have shown that having a learning disability did impact on the illness experience, and coping with its symptoms and treatments.

### **6.3 Clinical Implications**

There are a number of clinical implications that can be derived from this study and its results:

- Having a learning disability impacted on how a patient experienced and coped with stage V kidney disease and its treatments. The level of disability and

understanding of the patient had direct implications for coping with the illness and its various treatments.

- The results showed a number of ways in which the concept of coping could be constructed. For example, the consultants spoke of coping in terms of compliance and mood (perhaps physical and emotional coping), and ultimately of survival ('you don't cope, you die'). The families and carers spoke of coping in a number of ways; practical coping (how the patient managed the practical aspects of managing the illness), and emotional coping (such as the influence of low mood and feelings of hopelessness when transplant was not possible). It appeared that the completion of 'trials' may influence assessment of coping; the idea of getting through it meant the patient coped to some degree (for example, 'it was really difficult at the time, but he got through it and coped well all considering'). Other notions of coping included beneficial passivity - patients who allowed health care staff to perform numerous procedures ('when I wouldn't blame him for refusing'), how a lack of understanding could aid/hinder coping, and the carer's own coping. This indicates that when coping is discussed, different people may be focusing upon different aspects.
- The results highlighted how important the concept of coping is when making best interest decisions about treatment options. Coping and how it relates to the Mental Capacity Act (2005) and making best interest decisions should be investigated further by health services. It may be useful to research the role of coping in making best interest decisions further, and in perhaps developing coping assessment tools to help with making decisions.
- Having an awareness of what the individual patient brings (such as their previous experiences and understanding), the level and type of support they had that's available, the consultant (their role, awareness of power, and level of direct involvement), and the experience of hospital care, was important when thinking about how a patient with a learning disability copes.
- The families and carers in this study all described experiencing some level of impact because they cared for an individual with a learning disability and renal

failure. It may be important to regularly check with the carer that they are managing and have sufficient support themselves.

- Upon reflection, there was little discussion by the consultants about how patients with a learning disability may be empowered (for example, they spoke often about having to make decisions for them). This may not be specifically related to the patients having a learning disability; it could perhaps be more about how consultants generally feel and interact with their patients. It may be that health services and care delivery may benefit from further investigation around how to empower patients.
- In 2001 a campaign was launched called 'Nothing about us without us' (Department of Health, 2001b). A Service Users Advisory Group worked with the department of health over a year. They discussed their views about using services, and what they would like services to look like in the future. They made a number of points about healthcare that resonates with some of the findings of this project. They spoke about accessible information being made more available, and for staff to communicate information in a number of ways (such as drawing and pictures) to help aid understanding. One concern raised by a consultant in this study was the lack of accessible information made available for patients with a learning disability. However there were also examples of using visual information, such as the use of a DVD which one patient found useful. Another point made was that hospital stays need to be properly prepared for, and that operations may need even more preparation. This resonates with one parent's recommendation that formalised plans be put in place (discussed further in the next section about recommendations), and the experience of a female patient finding a sudden transplant operation scary and confusing. However, there were also examples in the current study of the service preparing, adapting and enhancing care for some patients (such as the preparation made for the patient with a severe needle phobia about to start dialysis).
- It's important to note that a number of recommendations made below are similar to those made by previous policy and legislation regarding learning disability and healthcare, such as those reviewed in the policy section of chapter

2. For example, in 2008 the Department of Health published the report Healthcare For All which investigated access to healthcare services for people with a learning disability. They recommended that:

- health services should make reasonable adjustments such as improving information,
- services should collect information about how they provide healthcare to patients with a learning disability,
- training around treating and supporting patients with a learning disability should be made available and incorporated into regular training for healthcare staff,
- the views of patients with a learning disability and their carers' should be taken into consideration when planning admissions and treatments.

Similar recommendations are made below by this study. This may indicate that these recommendations made by previous investigations are still important and require further work and development in order to help make services accessible and equal for individuals with a learning disability.

There are a number of recommendations that a healthcare service treating chronic illness or conditions may wish to consider:

1) Referral:

Consider the possibility of referral bias from primary healthcare sources and how any bias may be assessed and rectified.

2) Assessment and Planning:

Review and use the models produced in this study to help think in more detail about how patients with a learning disability may cope with illness. Perhaps using the models as a tool may aid thinking, planning and decision-making.

3) Treatment Choices and decision-making:



Produce and make available information that is accessible to aid patients with a learning disability understand what is or what might happen. For example, a DVD of what will happen if they are called in for a transplant. The patient and their family can then watch this as many times as they wish, over the years, to help prepare the patient. However, this research identified that the patients with a more severe learning disability were protected when waiting for a transplant by not being aware or understanding what is involved. But this lack of understanding then made the receiving of a transplant a scary and confusing experience. It may be that the consultant might wish to think through with the patient and their family about whether the possible long-term benefit of having some understanding would outweigh the potential hindrance of the patient finding this knowledge anxiety-provoking.

#### 4) Hospital admissions:

Formulate and introduce a plan, or planning system, that prepares the patient, their family and the hospital for the management of the illness and any inpatient stays that should occur. As one parent suggested:

*Family02: "...where I work if you've got something coming up you discuss it and, you know, formulate your plan, your ideas, and then put that into action. And I think there's a case for somebody like my son, getting together with somebody from the nursing staff and having a proper plan put in place. I don't think there ever was a plan for my son. There might have been but I didn't know about it. And that plan should say right how are we going to, who's gonna do this, who's gonna sort out that, how are we gonna ensure that...so that if they've got to go back to their health resources and say look this person needs more input, how're you gonna do it, somebody's gotta think through that to come up with a proper plan for it, I think that would be my main thing that ought to happen, because clearly they can't just drop into the system as it stands now and have it work for them".*

The researcher is aware of templates of plans currently being created and used in other trusts, such as the 'Acute Needs Risk Assessment Learning Disabilities' which is being finalised by the North Tees and Hartlepool NHS Foundation Trust, and the 'VIP Hospital Passport' published and used by Calderdale and Huddersfield NHS Foundation Trust. The plans assess and consider the patient's communication needs, care needs, support levels and so on in preparation for any admissions. Considering forming and

implementing an evaluation form that briefly interviews the patient, their carers and the staff about their care experiences could also help to identify good practices and improve others.

It may be helpful to consider further how patients with a learning disability are identified, and how they feel about that identification. A number of trusts are currently compiling a list or a system where a person's learning disability is 'flagged' in their notes (if they agree to opt in). Training about learning disability, its definition and recognition may be helpful for services who do not often come into contact with people who have a learning disability.

#### 5) Continue Researching the Experiences of Patients with a Learning Disability:

Carry on the research; healthcare and learning disability is a topic that is receiving significant attention. Consider if it is possible for the service or another party (such as their psychologist if they have one) to continue the research that has started in this project by talking to and interviewing patients with a learning disability, their carers, and the service.

## **6.4 Strengths and Limitations of the Study**

This research has a number of strengths both in design and in the findings. In 1999 Elliott, Fischer and Rennie published an influential paper describing a number of guidelines that can be used to evaluate the strength of qualitative research. These guidelines are now used to think further about the strengths of this research:

### A. Publishability Guidelines Shared by both Qualitative and Quantitative Approaches (p220):

1. Explicit scientific context and purpose: This study is underpinned by and has described explicit scientific context and purpose: that is, to begin to understand

how patients with a learning disability cope with being chronically ill. Clear research questions and aims were developed and employed.

2. **Appropriate methods:** This study has reviewed, chosen and demonstrated appropriate methods of data collection and analysis; by the use of semi-structured interviews to collect data, and analysis of the data using grounded theory.
3. **Respect for participants:** This study has demonstrated respect for participants in a number of ways; by obtaining ethical approval to carry out the study, by attempting to recruit patients with a learning disability (and creating accessible information and consent sheets), by producing information and consent sheets for consultant and family participants, by obtaining the participant's informed consent to take part, by being aware of internal confidentiality throughout, by interviewing in a time and place of the participant's choice (at their place of work or home), and by the researcher having information readily available should a participant request further support.
4. **Specification of methods:** This study reviewed in detail a number of methods of data collection (such as using questionnaires, focus groups, or interviews), and data analysis (IPA and grounded theory) and gave clear reasons for each choice and how they were employed in the research.
5. **Appropriate discussion:** This study has presented a discussion that describes in depth summaries of the results, how the findings can be integrated in current literature, and it presents a number of clinical implications, recommendations and suggestions for future research.
6. **Clarity of presentation:** This study has been written in clear, modern English. The models have been presented as well-sized, with clear print, in diagrammatic form on A3 paper. The appendix includes copies of a number of the sheets used in the research to aid further understanding as to how the research was carried out.
7. **Contribution to knowledge:** This study has demonstrated a dearth of literature and research regarding how patients with a learning disability cope with chronic illness. It has also evidenced why this is an important topic. Two models

have been produced that begin to explain this process, making a small but significant contribution to the field.

B. Publishability Guidelines Especially Pertinent to Qualitative Research (p220):

1. **Owning one's perspective:** The researcher has attempted to be aware of her own values, interests and beliefs that may relate to the research by discussing reflexivity and by writing a personal research journal and memo journal. For example, I have previously worked with people who have a learning disability. This has meant that at times I have taken on a type of advocacy role. I used the reflective diary to consider this role, and what potential effect this may have on my interactions with the participants and the data. In 1993 Stiles published a paper discussing how to optimise quality within qualitative research. He advised that researchers be aware of any findings they found surprising or unexpected in some way, which can help to demonstrate their openness to what may be found. Similarly, the researcher of this study noted some surprise at some of the results. For example, the researcher was aware of the idea that having a learning disability may possibly be protective, but was surprised at the emphasis and extent of protection that having a learning disability was described as having for some of the patients. The researcher also did not expect to find patients making efforts to hide their learning disability, and that this would impact on their coping experience.
2. **Situating the sample:** the researcher provided basic demographic data for the consultants, and described the characteristics of the patients talked about by their families and carers to aid the reader's understanding of their backgrounds and treatment experiences. It is also important to consider how the participants' may have situated themselves in relation to the researcher. For example, the researcher is a white female clinical psychology student, in her twenties, working for the NHS, trying to understand how patients with a learning disability may cope with renal failure. It may be that the younger female student role feels quite sympathetic and unthreatening, allowing the participants to feel they could safely discuss sensitive issues. Alternatively, the

researcher may have been viewed as a representative of the NHS, or as someone who will be in contact with the other participant group, perhaps causing some participants to be cautious when talking about care experiences.

3. Grounding in examples: The researcher has provided numerous examples of the data to illustrate the categories developed and the understanding of them. Examples have also been provided of coding and writing memos, and photographs of the analysis in action can be found in the appendix, which help to illustrate how the analysis took place.
4. Providing credibility checks: The researcher used a number of methods to check the credibility of the categories. Significant discussion took place within the research team and with supervisors; the researcher described in detail the accounts, categories and results, with the supervisors asking questions and offering critique and feedback. Elaborations and corrections were also suggested. The researcher also attended a qualitative research support group on three occasions to discuss with other qualitative researchers the intricacies and complexities of qualitative research and practice.
5. Coherence: The results and models are presented in a coherent way that demonstrates the integration of the accounts obtained, whilst still preserving and illustrating nuances (p223). The study provides a rich narrative explaining the results and models produced. The elements of each category are presented in detail with quotes used to aid understanding. Differences and interesting findings are also highlighted (for example, the differing focus on decision-making found between the carers and consultants). The themes that emerged from the two data groups fit together in two theoretical maps that visually demonstrate the categories and their relationships. Similar categories are grouped together, and the models use shapes and arrows to demonstrate relationships and their sequence.
6. Accomplishing general vs. specific research tasks: It was the aim of this research to begin to gain an understanding as to how individuals with a learning disability may cope with chronic illness by focusing more explicitly on the experiences of patients with chronic kidney disease. A good number of

participants were interviewed in depth (ten participants with most interviews lasting for at least an hour). These participants comprised of two different groups; consultants and families/carers, each with differing and important perspectives. The researcher was also mindful that the accounts of the participants are based on their experiences rather than those of the people with learning disabilities about whom they talk.

7. Resonating with readers: the study has been written in such a way (for example, by including a significant number of quotations from the participants) to try to bring the experiences of the participants, and the individuals they are describing, to life. It is hoped by the researcher that the significant level of openness and honesty the participants demonstrated in their accounts has been effectively communicated so that all readers are able to understand and connect to the experiences described.

As described above, this study has a number of strengths. It also however has a number of limitations that should be considered. For example, it is difficult within research when the researcher needs to rely on another party to identify and contact the possible participants. It cannot be guaranteed that all the possible participants were offered the opportunity to participate, and that of those who were sent the information and invited to take part, that they all should have been. Because the potential patient participants (and their families) were identified by the consultants who work within the renal service, there is the possibility of a number of selection biases. It is unlikely but possible that the consultants may have named patients and families who they believed would be more likely to give a good review of the service.

It is also a possibility that the consultants may have more easily remembered patients with a moderate or severe learning disability (the more severe the learning disability, the more evident and memorable it may be). It is possible that the consultants may not recognise and name patients with a mild learning disability; interestingly, this issue was actually raised by the consultants within the interviews. If the consultants name patients who they think may have a learning disability but are not sure, and there is no

strong evidence in the patient's records that they have been diagnosed with or evident recognition that they have a learning disability, they will not have been approached. This means that patients with a mild learning disability may have been less likely to be selected than those with a more severe learning disability. These potential difficulties were partly guarded against by the production and use of a detailed information sheet regarding learning disability, capacity and inclusion criteria that aided the consultants when they attempted to identify potential participants. Unfortunately it is not possible to say whether these biases were definitely successfully guarded against.

It is also a possibility that the design of the recruitment process may have meant that families of patients who significantly struggled to cope with dialysis were less likely to be recruited. The consultants spoke of a number of patients who were unable to cope with dialysis and died. This study did not interview families whose family member had died; those who for some reason may not have been able to cope. Therefore, the experiences of families whose family member were unable to cope with dialysis and died as a result were not included.

Despite the original intentions of the researcher to interview patients with a learning disability, this was not possible. So unfortunately, the group of people that are most central to this research have not been interviewed. A further consideration for future research is therefore to interview the patients themselves. End stage renal failure is quite a rare illness. Individuals with a learning disability who have renal failure are quite a restricted and small population. It might be that focusing on other areas of ill health that are more common to people with a learning disability may yield a better potential for participants. For example, obesity and diabetes is a 'common' health issue for people with a learning disability (Merrick and Morad, 2010), and up to 50% of people with Down's Syndrome (which always co-occurs with a learning disability; Connolly, 1978) are born with congenital heart defects (Hellings, Butler & Grant, 2010). Including various health conditions could add additional and valuable information to the learning disability, illness and coping research base.

Finally, it is possible that this type of research is best implemented as an ongoing service evaluation project, where the researcher who is implementing it is part of the service and aware of when patients with a learning disability attend. The researcher may then be able to build, over time, a picture of how patients with a learning disability cope with being ill.

## **6.5 Considerations for Future Research**

There are a number of important issues raised within this study that future research could investigate. As stated above in the limitations discussion, further research that includes accounts from patients with a learning disability and renal failure and from individuals with a learning disability coping with other chronic illnesses, could significantly aid understanding and add to the developing research in this area. Research into other chronic illnesses could again include accounts from health care staff (such as consultants) and family members/carers.

The research in coping with renal failure may also be developed further. This study interviewed and analysed data from consultants, who are important as they are the gate-keepers to treatment. It may also be useful to interview and add the experiences of frontline nursing and ward staff about how patients cope with being in the hospital, receiving treatment and being unwell. Further research into the role of coping and assessment of coping in making best interest decisions may also yield further important findings and guidelines.

One consultant raised an issue about the possibility of a referral bias from primary healthcare to the hospital services. Further research that looks at chronic illness and individuals with a learning disability accessing speciality services (such as kidney disease and the renal service) may help to confirm if there are referral difficulties present.



Another area of further design and investigation may be in developing coping aids (such as accessible information, inpatient plans and care evaluations) and researching their effectiveness and possible influence on illness experience and coping. The development of such aids and exploring if they aid coping may help services improve the patients', their families and the services experiences of managing chronic illness. Linked to this idea is the design and development of decision aids. Decision aids may be of help during decision-making processes, for example in making treatment decisions (such as whether to dialyse) which this study has found can often be a complex and difficult process.

## **6.6 Concluding Comments**

The aims of this research were to produce two models of how patients with a learning disability may cope with stage V kidney disease and its treatments. Whilst it is unfortunate that one of these models has not emerged from data derived from the patients themselves, these two models are hopefully a significant step in the right direction. As the researcher I am encouraged by the wealth and quality of the information and experiences uncovered by the research, and the potential there appears to be for a wide variety of future research and investigations. The other aim of this research was to add some insight and understanding to a very small research base about how people with a learning disability cope with chronic illness; it is the belief of the researcher that this study does.

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## **Appendix**

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## Appendix 1: REC and R&D Approval Letters

**NHS**

**National Research Ethics Service**

**Bradford Research Ethics Committee**  
Yorkshire & Humber REC Office  
Millside  
Mill Pond Lane  
Meanwood  
Leeds  
LS6 4RA

Telephone: 0113 305 0116

22 September 2010

Miss Elspeth Read  
Psychologist in Clinical Training  
The Leeds Teaching Hospitals NHS Trust  
Leeds Institute of Health Sciences,  
Charles Thackrah Building,  
101 Clarendon Road, Leeds  
LS2 9LJ

Dear Miss Read

**Study Title:**                    **How Patients with a Learning Disability Cope with Chronic Kidney Disease; a Qualitative Study of Accounts from Patients and Consultants.**

**REC reference number:**    **10/H1302/52**

Thank you for your letter responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

**Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

**Ethical review of research sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

**Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research

This Research Ethics Committee is an advisory committee to Yorkshire and The Humber Strategic Health Authority  
The National Research Ethics Service (NRES) represents the NRES Directorate within  
the National Patient Safety Agency and Research Ethics Committees in England

governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.*

*Sponsors are not required to notify the Committee of approvals from host organisations.*

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Investigator CV	E Read	
Investigator CV	G Latchford	
Investigator CV	T Isherwood	
Protocol	1	
REC application		05 July 2010
Covering Letter		07 June 2010
Interview Schedules/Topic Guides	Patients V1	
Interview Schedules/Topic Guides	Consultants V1	
Response to Request for Further Information		01 September 2010
Participant Information Sheet: For Consultants	1	
Participant Information Sheet: For Families and Carers	1	
Participant Information Sheet	1	
Participant Consent Form	1	
Participant Consent Form: For Consultants	1	
Information Letter for Trainee Clinical Psychology Research	1	
Identification and Recruitment Protocol	2	01 August 2010
Letter from Dr A F Mooney, Consultant Renal Physician		17 August 2010
Evidence of insurance or indemnity	08/10/2009	

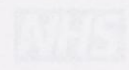
#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views



known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroup@nres.npsa.nhs.uk](mailto:referencegroup@nres.npsa.nhs.uk).

**10/H1302/52** **Please quote this number on all correspondence**

Yours sincerely

**Professor Alan Roberts  
Chair**

Email: [Claire.kelly@leedspft.nhs.uk](mailto:Claire.kelly@leedspft.nhs.uk)

Copy to: *Mrs Rachel E De Souza*

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis outlined in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The following research sites have been approved for the study, subject to the following conditions being met prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study:

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant NHS organisation(s) in accordance with NHS research

The Leeds Teaching Hospitals **NHS**  
NHS Trust

Ref: Amy Dickinson

19/10/2010

Research & Development

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Dear Miss Elspeth Read

**Re: LTHT R&D Approval of: Learning Disability and Renal Failure**  
**LTHT R&D Number: RL10/9427**  
**REC: 10/H1302/52**

I confirm that this study has R&D approval and the study may proceed at The Leeds Teaching Hospitals NHS Trust (LTHT). This organisational level approval is given based on the information provided in the documents listed below.

In undertaking this research you must comply with the requirements of the *Research Governance Framework for Health and Social Care* which is mandatory for all NHS employees. This document may be accessed on the R&D website [http://www.leedsth.nhs.uk/sites/research\\_and\\_development/](http://www.leedsth.nhs.uk/sites/research_and_development/)

R&D approval is given on the understanding that you comply with the requirements of the *Framework* as listed in the attached sheet "Conditions of Approval".

If you have any queries about this approval please do not hesitate to contact the R&D Department on telephone 0113 392 2878.

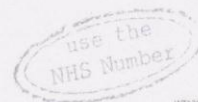
#### Indemnity Arrangements

The Leeds Teaching Hospitals NHS Trust participates in the NHS risk pooling scheme administered by the NHS Litigation Authority 'Clinical Negligence Scheme for NHS Trusts' for: (i) medical professional and/or medical malpractice liability; and (ii) general liability. NHS Indemnity for negligent harm is extended to researchers with an employment contract (substantive or honorary) with the Trust. The Trust

Chairman Mike Collier CBE Chief Executive Maggie Boyle

The Leeds Teaching Hospitals incorporating:

Chapel Allerton Hospital Leeds Dental Institute Seacroft Hospital  
St James's University Hospital The General Infirmary at Leeds Wharfedale Hospital

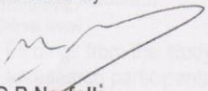


WT282

only accepts liability for research activity that has been managerially approved by the R&D Department.

The Trust therefore accepts liability for the above research project and extends indemnity for negligent harm to cover you as principal investigator and the researchers listed on the Site Specific Information form. Should there be any changes to the research team please ensure that you inform the R&D Department and that s/he obtains an employment contract with the Trust if required.

Yours sincerely

  
**Dr D R Norfolk**  
 Associate Director of R&D

#### Approved documents

The documents reviewed and approved are listed as follows

<i>Document</i>	<i>Version</i>	<i>Date of document</i>
NHS R&D Form	3.0	07.06.2010
SSI Form	3.0	07.06.2010
Directorate Approval		10.08.2010
Protocol	<i>No Version</i>	<i>Not Dated</i>
REC Letter confirming favourable opinion		22.09.2010
Participant Information Sheet (REC Approved) <i>Patient</i>	<i>No Version</i>	<i>Not Dated</i>
Participant Consent Form (REC Approved) <i>Patient</i>	<i>No Version</i>	<i>Not Dated</i>
Participant Information Sheet (REC Approved) <i>Families &amp; Carers</i>	<i>No Version</i>	<i>Not Dated</i>
Participant Information Sheet (REC Approved) <i>Consultants</i>	<i>No Version</i>	<i>Not Dated</i>
Participant Consent Form (REC Approved) <i>Consultants</i>	<i>No Version</i>	<i>Not Dated</i>
Information Letter (REC Approved) <i>Trainee Clinical Psychologist</i>	<i>No Version</i>	<i>Not Dated</i>
Interview Schedule (REC Approved) <i>Patient</i>	<i>No Version</i>	<i>Not Dated</i>
Interview Schedule (REC Approved) <i>Consultant</i>	<i>No Version</i>	<i>Not Dated</i>
Identification and Recruitment Protocol (REC Approved)	<i>No Version</i>	<i>Not Dated</i>
Evidence of Insurance		08.10.2009





## National Research Ethics Service

### Bradford Research Ethics Committee

Yorkshire & Humber REC Office  
Millside  
Mill Pond Lane  
Meanwood  
Leeds  
LS6 4RA

Tel: 0113 305 0116

21 March 2011

Miss Elspeth Read  
Psychologist in Clinical Training  
The Leeds Teaching Hospitals NHS Trust  
Leeds Institute of Health Sciences,  
Charles Thackrah Building,  
101 Clarendon Road, Leeds  
LS2 9LJ

Dear Miss Read

**Study title:** How Patients with a Learning Disability Cope with  
Chronic Kidney Disease; a Qualitative Study of Accounts  
from Patients and Consultants.  
**REC reference:** 10/H1302/52  
**Amendment number:** 1  
**Amendment date:** 03 February 2011

The above amendment was reviewed at the meeting of the Sub-Committee held on 07 March 2011.

#### Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

#### Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Interview Schedules/Topic Guides	1	
Participant Consent Form	1	
Participant Information Sheet	2	
Protocol	3	21 January 2011
Notice of Substantial Amendment (non-CTIMPs)		03 February 2011

#### R&D approval

This Research Ethics Committee is an advisory committee to the Yorkshire and The Humber Strategic Health Authority  
The National Research Ethics Service (NRES) represents the NRES Directorate within  
the National Patient Safety Agency and Research Ethics Committees in England

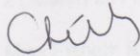
All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**10/H1302/52: Please quote this number on all correspondence**

Yours sincerely



**Miss Claire Kelly  
Committee Assistant Co-ordinator**

E-mail: [Claire.kelly4@nhs.net](mailto:Claire.kelly4@nhs.net)

Copy to: Mrs Rachel de Souza, University of Leeds

10/H1302/52  
1 February 2011

The following document was reviewed at the meeting of the Sub-Committee held on 07 March 2011

Dr [Name]

The members of the Committee being that in the research plan a favourable ethical opinion of the amendment to the study described in the notice of amendment form and supporting documentation.


Approved documents

The documents reviewed and approved at the meeting were:

Protocol	1 February 2011
Notice of Substantial Amendment (NOSA) 10/H1302/52	10 February 2011

R&D approval

The Research Group Committee is an advisory committee at the University of Leeds and the wider Yorkshire Health Region. The National Research Ethics Service (NRES) regulates the R&D Committee within the National Health Service and is responsible for R&D committees in England.

The Leeds Teaching Hospitals   
NHS Trust

Ref: Amanda Burd

27/04/2011

Research & Development Directorate

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Dear Miss Elspeth Read

Re: **LTHT R&D Number: RL10/9427 Learning Disability and Renal Failure**  
**REC: 10/H1302/52**

Thank you for your letter dated 21/03/2011 regarding amendment 1 to the above research study.

The amendment may be implemented with immediate effect in the Leeds Teaching Hospitals NHS Trust under the existing NHS Permission. Please note that you may only implement changes described in the amendment notice or letter.

Continued NHS Permission for the project is subject to the following conditions:

- Research Ethics Committee approval for the amendment, if required, has been obtained
- Any contractual arrangements relating to this change have been addressed
- The Research Lead/Clinical Director for the Directorate has approved any resource implications for the Directorate

If you have any queries about this acknowledgement please do not hesitate to contact the R&D Department on telephone (0113) 392 2878.

With kind regards

Yours sincerely

  
Dr. D R Norfolk  
Associate Director of R&D

## Appendix 2: Information Sheet about Learning Disability and Capacity



**UNIVERSITY OF LEEDS**  
Doctor of Clinical Psychology Programme

### IDENTIFICATION OF PATIENTS WITH A LEARNING DISABILITY IN THE RENAL SERVICE

#### The Learning Disability and Renal Failure Research Project

My name is Elspeth Read and I am a psychologist in clinical training. As part of my clinical psychology doctorate, I am carrying out some research within the renal service of St James' Hospital looking at how patients with a learning disability cope with stage V renal failure (as an example of a chronic illness). I am hoping to interview patients who have a learning disability and a diagnosis of stage V renal failure.

It would be very helpful if you could provide Dr Andrew Mooney (Consultant Nephrologist) with the names of patients you believe have a diagnosis of stage V renal failure AND

- 1) Have a learning disability AND
- 2) Have the capacity to consent to the interview

Below is a checklist that may hopefully aid you in this task:

#### 1) Does the patient have a learning disability?

This may be apparent from the patient's notes, their history and their presentation. This study uses ICD-10 criteria regarding the presence of learning disability:

- Significant impairment of intellectual functioning (often evidenced by low IQ(<70)/special school/statement of educational need/self report/involvement of LD services).
- Significant impairment in adaptive/social functioning (the individual struggles with everyday tasks and may need substantial support with self care/cooking/budgeting/travel etc).
- These difficulties have been present since childhood.

#### 2) Does the patient have the capacity to consent to the interview?

The Mental Capacity Act (2005) states that an individual must be assumed to have capacity until it is established that s/he lacks capacity. A person is not to be treated as unable to make a

decision unless all practicable steps to help him or her to do so have been taken without success.

A patient can be included **unless** you believe they would be **unable** to:

- Understand the information relevant to the decision to take part in the study ;
- Retain that information;
- Use or weigh the information as part of the process of making the decision;
- Communicate the decision made.

Like the rest of the population, patients with a learning disability may have other diagnoses or co-morbidities such as secondary physical illnesses, mental illness or other behavioural or emotional difficulties. **The presence of another illness or difficulty should not exclude the patient from the study**, unless you have a significant concern that the effect of such means the patient is unlikely to have capacity to consent to the interview.

**Your assistance is vital in the identification of patients suitable for this study.**

Please pass on the names of the patients who you believe meet the above criteria to Dr Mooney. In proposing names you are indicating that the patient has a learning disability AND you believe that in principle they retain sufficient capacity to consent to the study.

If you are in any doubt regarding the presence of evidence of learning disability or the impact on capacity, Dr Rachel Attfield (Clinical Psychologist) and Dr Gary Latchford (Consultant Clinical Psychologist) would be happy to discuss these issues with you.

THANK YOU for your time and help.

### Appendix 3: Participant Information Sheet for Consultants



**UNIVERSITY OF LEEDS**  
Doctor of Clinical Psychology Programme

#### Participant Information Sheet for Consultants

<i>Title of Study:</i>	How Patients with a Learning Disability Cope with Chronic Kidney Disease; a Qualitative Study of Accounts from Patients and Consultants.
<i>Principle Investigator:</i>	Elsbeth Read, Psychologist in Clinical Training
<i>Supervisors:</i>	Dr Tom Isherwood, Consultant Clinical Psychologist/Clinical Tutor Dr Gary Latchford, Consultant Clinical Psychologist/Research Director Dr Janette Moran, Principal Clinical Psychologist
<i>Contact Details:</i>	Clinical Psychology Admin Office University of Leeds Charles Thackrah Building 101 Clarendon Road Leeds, LS29 9LJ.  Email: <a href="mailto:umemr@leeds.ac.uk">umemr@leeds.ac.uk</a>

#### **About Me**

I am a Psychologist in Clinical Training on the University of Leeds clinical training programme. I am currently undertaking a research project that looks at how patients with a learning disability cope with stage V renal failure. I am asking for your help and participation with this project.

#### **Why have you been invited to take part in the study?**

You have been invited to take part in the study because you are currently a Consultant Nephrologist working for the Teaching Hospitals NHS Trust regional renal service.

#### **What is the Purpose of the Study?**

Healthcare for patients with a learning disability is an important topic. Over the past few years it has received increased attention and media focus, and has been prioritised by the NHS and government in terms of improving the access and experience of healthcare services for this

patient group. There is, however, a paucity of research and little understanding as to how patients with a learning disability experience and cope with chronic illness.

This qualitative study will look at how patients with a learning disability cope with the chronic illness kidney disease; more specifically stage V renal failure. As I'm sure you'll appreciate, renal failure is an important example of a chronic disease. It involves the making of a number of difficult decisions and adherence to complicated and difficult treatment regimes. The major form of treatment for chronic kidney disease, dialysis, requires large adjustments to be made by the individual, increases the likelihood that the individual may experience symptoms of depression, and can have significant detrimental effects upon quality of life. Six patients with a learning disability diagnosed with stage V renal failure and six consultants will be interviewed. The interviews will be semi-structured, and the data will be analysed using Grounded Theory analysis.

The main aims of the research will be:

- To add insight and understanding to a small research base about how people with a learning disability may cope with a chronic illness and its treatment.
- To use grounded analysis to produce a model of how people with a learning disability cope with chronic kidney disease.

Consultants have the responsibility for the health and treatment of patients under their care. The decision as to whether or not a patient will be able to cope with the difficult treatments for stage V renal failure will have important implications as to whether that treatment is offered. Therefore, accounts from consultants of how patients with a learning disability cope with chronic kidney disease and its treatments are very important in addressing the aims of the research.

### **What will be involved if I take part in the study?**

If you decide to take part in the study we will arrange a time to meet at St James' Hospital that is convenient for you. You will be asked to sign a consent form, and then the interview will take place. The interview will last approximately half an hour (or up to an hour if needed). It will be semi-structured, and will involve you talking about experiences that you have had treating patients with a learning disability, how they have coped, and the issues around this patient group and coping with renal failure.

**Will information obtained in the study be confidential?**

The interview will be recorded on a digital dictaphone, and transcribed. The interview will be immediately transferred to an encrypted memory stick, and the digital recording deleted. All transcripts and any interview content used will be anonymous. The memory stick, consent form and transcript will be stored in a locked cabinet within the Clinical Psychology department at the University of Leeds for a period of three years. Following this period they will be destroyed.

**What happens if I do not wish to participate in this study or wish to withdraw from the study?**

Taking part in this study is voluntary. If you do not wish to participate in this study, or you wish to withdraw from the study at any time you can do without giving any reasons for your decision. Your decision to withdraw will be confidential.

**I want to take part. What happens next?**

If you are interested in taking part in this study, please reply to this email with your preferred contact details (for example, your telephone number or email address). I'll contact you to arrange a date and time for the interview that would be convenient for you. We will then meet at the arranged time at St James's Hospital, go through the consent procedure and commence with the interview.

If you have any queries please don't hesitate to contact me on the above details.

**Thank you for reading this information and I look forward to meeting you.**

Elsbeth Read

Date



## Appendix 4: Participant Information Sheet for Family and Carers



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Doctor of Clinical Psychology Programme

### Project Information Sheet for Family and Carers (version 2)

#### About me

My name is Elspeth Read. I am a Psychologist in Clinical Training on the University of Leeds clinical psychology training programme. I am currently undertaking a research project that looks at how patients with a learning disability cope with kidney disease. I am writing to your family member and yourself asking for help and participation with this project.

#### About the Project

Healthcare for patients with a learning disability is an important topic. Over the past few years it has received increased attention and media focus, and has been highly prioritised by the NHS and government. However, there are few projects that have actually asked the patients themselves for their own accounts and feelings about their health problems. This project hopes to begin to change this.

In particular, there is little understanding about how patients with a learning disability cope with more chronic illnesses. This project aims to look at how patients with a learning disability cope with the chronic illness kidney disease. Kidney disease is an important example of a chronic illness; it involves making a number of difficult decisions and having to adjust to complicated and difficult treatment regimes such as dialysis.

The main aims of this project are:

- To add insight and understanding to a small research base about how people with a learning disability may cope with a chronic illness and its treatment.
- To produce a psychological model of how people with a learning disability cope with chronic kidney disease.

A further result may be:

- The project may highlight good practice within the renal service with relevance for other services, or identify needs that are not currently met.
- It may also produce further considerations for the service such as indications for further training.

### **Why have I been sent this information?**

For any individual with an illness, family, friends and carers play an important supportive role. This sheet has been designed to inform you about this study in which you and your family member have been invited to participate.

### **What will be involved in participating in the project?**

If your family member agrees to help with the project, and is able to give their informed consent, they will be interviewed by myself. If you also agree to take part in the project you will be interviewed as well. I will contact you both about arranging a time that is convenient. We can meet either at your home or at hospital, whichever is preferred. I will then meet with you and your relative and we will talk in more detail about taking part and consent. You and your family member will be asked to sign a consent form, agreeing to take part in the project. The interview will then take place. It is the decision of your family member and yourself as to whether you would like to be interviewed together. We will talk about what it is like to have and to live with kidney disease. The interview will last from half an hour to an hour in length.

The account, experiences and information given by yourself and your family member in the interview about what it is like to live with kidney disease, will provide valuable insight and understanding. Such insight and understanding will help healthcare professionals and services to support individuals through the illness.

### **Will information obtained in the interview be confidential?**

The interview will be recorded on a digital dictaphone, and transcribed. The interview will be immediately transferred to an encrypted memory stick, and the digital recording deleted. All transcripts and any interview content used will be anonymous. The memory stick, consent form and transcript will be stored in a locked facility within the University of Leeds for a period of three years. Following this period they will be destroyed.

Participation in the project will be confidential; the renal service at St James' hospital will not be informed of who is (or who isn't) taking part. The decision to take part or not will have no effect upon the healthcare your family member receives from the service.

**What happens if me and/or my family member does not wish to participate in this project or wishes to withdraw from the project?**

Taking part in this project is voluntary. If you or your family member do not wish to participate in this project, or wish to withdraw from the study at any time, you and/or they can do so without giving any reasons for the decision. The decision to withdraw will be completely confidential. St James's Hospital renal service will not be informed of who is participating or who is not. Withdrawing from the study will have no effect upon the healthcare your relative receives from the service.

**Me and/or my family member want to take part. What happens next?**

If you and/or your family member would like to take part you/they can either contact me by telephone, or fill in the consent form that came in this pack and send it back in the stamped, addressed envelope provided. Alternatively, if your family member would like for you to contact me on their behalf, that is also welcomed. Please don't hesitate to contact me on the number given below. Arrangements will then be made for the interview to take place.

If you or your family member have any questions about the project, please don't hesitate to contact me on the details below.

**Thank you very much for reading this information sheet.**

Elsbeth Read

Date

*Contact Details:*

Clinical Psychology Admin Office  
University of Leeds  
Charles Thackrah Building  
101 Clarendon Road  
Leeds, LS29 9LJ.

Tel: 0113 343 2732

Email: [umemr@leeds.ac.uk](mailto:umemr@leeds.ac.uk)

## Appendix 5: Consultant Consent Form



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### Consent Form for Consultants

Please delete as appropriate then initial

I have read the participant information sheet Y/N .....

I have had the opportunity to ask questions and discuss the study Y/N .....

I am satisfied with the answers to my questions Y/N .....

I have received enough information about this study Y/N .....

I understand that I am free to withdraw from this study at any stage without giving a reason Y/N .....

I agree to take part in this study Y/N .....

Signature .....

Name .....

Date .....

### Appendix 6: Family/Carer Consent Form



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## Consent Form for Family and Carers

Please delete as appropriate then initial

I have read the participant information sheet Y/N .....

I have had the opportunity to ask questions and discuss the study Y/N .....

I am satisfied with the answers to my questions Y/N .....

I have received enough information about this study Y/N .....

I understand that I am free to withdraw from this study at any stage without giving a reason Y/N .....

I agree to take part in this study Y/N .....

Signature .....

Name .....

Date .....

## **Appendix 7: Consultant Interview Schedule**

### Interview Schedule for Consultant Participants

- *Introduction*

Make introductions.

Thank you for meeting me here today. Before we begin, I would like to go through the information sheet and consent form.

[Participant gives informed consent and signs form]

- *The Interview*

As you know, I'm conducting some research looking at how patients with a learning disability cope with renal failure.

I was wondering if we could begin by thinking about some experiences you've had treating patients with a learning disability.

Do you feel there are any differences in treating patients with a learning disability in comparison to patients who do not?

Do you feel there are any particular issues or challenges working with this group?

Can you think of any patients that did not perhaps cope well with the illness or its treatment?  
Do you have any ideas about why they may have found these particular aspects difficult to cope with?

Can you think of any patients that coped well with the illness and its treatments? Why do you believe they coped better?

Do you have any ideas about what may help patients with a learning disability cope with renal failure and its treatments? And conversely what may not help?

Does the presence of a learning disability change or affect the decision making process about choice of treatment (e.g.dialysis or transplant)? Can you tell me about this process?

Do you have any thoughts about how consultants themselves cope with treating patients with a learning disability?

Do you have any thoughts about how the service copes with treating patients with a learning disability?

- *Ending*

Do you have anything else you would like to tell me about how patients with a learning disability cope with renal failure?

Debrief – how has it been talking to me today?

Reaffirm the process of data storage and destruction.

Results – When the project is complete I will present my findings to the department, which you are more than welcome to attend. I will send out more information about this closer to the time.

Thank you for talking to me today.

## **Appendix 8: Family/Carer Interview Schedule**

### Interview Schedule for Family/Carer Participants Version 1

- *Introduction*

Make introductions.

Thank you for coming along here today to meet with me. To start I would like to go through some important points about today, and then if you would like to stay and talk to me, we will then think and talk about what it is like to have kidneys that don't work properly.

First, I would like to talk about some important points about today. [Go through project information and obtain consent].

Do you have any questions about this that you would like to ask?

Let's begin.

- *Onset of illness*

I was wondering if we could go back a bit and think about when your family member first started to feel poorly. Can you tell me about that time?



Prompts about the onset of the illness – when, what the initial symptoms were, what this was like, how did their relative feel, initial beliefs, first meeting the doctors and nurses, how did life begin to change for their relative.

What happened then?

Ask about decision making process for dialysis. What happened?

- *Life in the present*

Can you tell me a little about what life is like for your family member at the moment with kidney disease?

Coping with symptoms – how does the illness make them feel? Are there things that they cannot do anymore? How else has their life changed? How has your life changed? etc

Coping with dialysis - Can you tell me about the dialysis? (what does it involve, what is it like, how does it affect your family member's life, how does it affect your life, what do you believe the future holds, what is the worst thing about dialysis, what is the best thing about dialysis, has dialysis caused any changes in your life, what are these changes, how have they and you managed with dialysis etc).

Have you and your family member had to think about different treatments and choose between them? Can you tell me about this?

(If appropriate) Coping with transplant – can you tell me about having the transplant (what happened, what was it like, what is life like now with a transplant, how is it different to life before, what will life be like in the future with the transplant etc.)

- *Compared to life before*

Is life *now* different to how life was before the illness? How was it different? What has changed? What have these changes been like for your family member? and you? How do you feel about these changes? Do you think there will be more changes?

- *Life in the future*

What do you think life is going to be like in the future? What will happen with the illness? What will happen with dialysis? Will there be more changes in your family member's (and your) daily life?

- *The ending*

Is there anything else about kidney illness that you would like to tell me about?

Debrief – what has it been like talking to me today? How has it felt? How do you feel now?

Data storage – explain again about the storage and destruction of the data.

Questions – do you have any questions about anything I have said or asked you about today?

Thank you very much for talking to me today.

**Appendix 9: Photographs of the Analysis in Action**

