A Qualitative Study to Explore the Experiences of Patients with Encapsulating Peritoneal Sclerosis

A Thesis Submitted to the University of Manchester for the Degree of Doctor of Philosophy (PhD)

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Abstract

Background

Although relatively rare, encapsulating peritoneal sclerosis (EPS) is nonetheless a major concern within the renal community. Risk of developing EPS is associated with long-term peritoneal dialysis. Surgery now offers better outcomes. Research into EPS continues to focus on imaging and early detection methods, genetics, biomarkers and preventive strategies. No previous studies have examined patients’ experiences of EPS, or their perception of the effect of EPS on health-related quality of life.

Aims

The aim of the present study was to explore the experience of patients who have undergone surgery for EPS in one centre in the north of England.

Methods

Nine participants were recruited out of a total of 18 eligible. Most participants were interviewed twice conducted on two occasions over a 12-month period. This was October 2009 to October 2010.

Analysis

Interpretative data analysis was conducted, following the philosophical tradition of hermeneutics. Following the first interview a summary was sent to each participant before the second interview. Both interviews were analysed and are presented as themes.

Results

EPS presents the biggest challenge these patients have had to face since developing chronic kidney disease. Three major themes were identified each with subcategories: 1. Understanding EPS -self interpretation, ‘not being heard’, gaps in information and knowledge, diagnosis shock and relief-confronting death 2. EPS an embodied experience- endurance, bodily awareness from others and within, struggles with eating 3. Adjustments and Transitions ‘A journey of survival’- losses, support structures and their impact and locating self.

Conclusions

The findings of this study highlight a number of important issues relevant to clinical practice, including lack of information and understanding of EPS, particularly its early symptoms, the extent of the surgery and the support required. At the time patients transfer from peritoneal to haemodialysis, the provision of adequate information about the risks and potential early signs of EPS may improve not only their experiences but in addition may assist its early detection.
Declaration

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.
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Dedication

I would like to dedicate this thesis to my family, my husband and son who have sacrificed more than just time. I am forever grateful for their love and support.
Acknowledgements

There are many individuals who I need to acknowledge and thank in what has been and intense three years of work.

Firstly I would like to specially thank the patients and their families who participated in this study. They welcomed me into their homes to share some often difficult and emotional feelings. I hope I have done justice in the representation of their experiences; more poignantly are those who have sadly died and so I am no longer able to share with them the final outcome.

I would like to acknowledge and thank my supervisors Professor Ann Caress and Professor Kinta Beaver who provided guidance, support and belief that I could achieve this. For Professor Beaver who stayed as my supervisor, even after leaving The University, so we could see it through to the end.

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The Author

Helen Hurst qualified as a nurse in 1989 and has undertaken a variety of roles within renal medicine. While working as a specialist renal community nurse she was in 1999 awarded a BA (Hons). She went on to gain a full-time MSc in clinical nursing and became an Advanced Nurse Practitioner within the peritoneal dialysis unit at Manchester Royal Infirmary. This allowed her to take a leading role and undertake research in encapsulating peritoneal sclerosis (EPS), particularly its early detection and the use of computerised tomography to assess changes in the peritoneum. Having observed and managed a range of patients who had developed EPS, Helen became increasingly aware that there were areas of practice without clear answers. The opportunity to undertake the present research came at a time when the renal community as a whole was trying to understand the implications and risks associated with EPS.
# Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>APD</td>
<td>Automated peritoneal dialysis</td>
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<tr>
<td>CAPD</td>
<td>Continuous ambulatory peritoneal dialysis</td>
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<tr>
<td>CASP</td>
<td>Critical Appraisal Skills Programme; NHS Critical Success Programme</td>
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<tr>
<td>CINAHL</td>
<td>Cumulative index to nursing and allied health literature</td>
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<tr>
<td>CKD</td>
<td>Chronic kidney disease</td>
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<tr>
<td>CRD</td>
<td>NHS Centre for Research and Dissemination, University of York</td>
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<td>CRF</td>
<td>Chronic renal failure</td>
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<tr>
<td>CT</td>
<td>Computerised tomography</td>
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<td>DH</td>
<td>Department of Health</td>
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<td>EBSCO</td>
<td>EBSCO Industries, Inc., a company providing an electronic search for journals</td>
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<tr>
<td>EPS</td>
<td>Encapsulating peritoneal sclerosis</td>
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<tr>
<td>ESRD</td>
<td>End-stage renal disease</td>
</tr>
<tr>
<td>ESRF</td>
<td>End-stage renal failure</td>
</tr>
<tr>
<td>HCP</td>
<td>Healthcare professional</td>
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<td>HD</td>
<td>Haemodialysis</td>
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<td>HHD</td>
<td>Home haemodialysis</td>
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<tr>
<td>IPA</td>
<td>Interpretive phenomenological analysis</td>
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<tr>
<td>ISPD</td>
<td>International Society for Peritoneal Dialysis</td>
</tr>
<tr>
<td>NHS</td>
<td>National Health Service</td>
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<tr>
<td>NICE</td>
<td>National Institute for Health and Clinical Excellence</td>
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<tr>
<td>NSF</td>
<td>National service framework</td>
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<tr>
<td>NSCAG</td>
<td>National Specialist Commissioning Advisory Group</td>
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<tr>
<td>PD</td>
<td>Peritoneal dialysis</td>
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<tr>
<td>QOL</td>
<td>Quality of life</td>
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<tr>
<td>RCT</td>
<td>Randomised control trial</td>
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<td>RRT</td>
<td>Renal replacement therapy</td>
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Chapter 1: Introduction

Encapsulating peritoneal sclerosis (EPS) is a rare but life-threatening complication of peritoneal dialysis (PD). This research takes the form of an exploratory study to gain an insight into the experiences of patients who have been diagnosed with the condition.

The impetus for the study has arisen from professional experience with patients suffering from chronic kidney disease (CKD) who have been undergoing PD but have then been diagnosed as having EPS. My close involvement in the care of these patients has raised concerns about the complexities in the way communication, support and care are provided. A deeper understanding of patients’ experiences will provide insights into how individuals face the challenge presented by EPS and will address some of the fundamental questions currently causing concern to clinicians.

Some of these concerns relate to the time the condition should best be directly discussed with patients. All patients diagnosed with CKD reach a period when a choice has to be made between the various dialysis options and the alternative of conservative management (opting not to undergo dialysis). The emphasis is on informed choice and patient participation in the decision, and is driven both by policy (DH 2004, Nice 2011) and research (Breckenridge and Locking-Cusolito 1997, Caress 1997, Kelly-Powell 1997, Tweed and Ceaser 2005, Landreneau and Ward-Smith 2006). One element in reaching an informed decision is ensuring that patients have accurate information, including the risk factors and possible complications. Patients who chose PD as a therapy make those decisions based on a set of beliefs around lifestyle and flexibility of the treatment (Morton et al 2010).

Many clinicians consider it best to discuss EPS at the start of this process, in other words at the time patients are presented with the choices open to them for their future treatment. On the other hand EPS is a rare complication and its risk becomes more significant after five years on PD treatment, yet the majority of patients do not reach the five year point. Hence the dilemma – it may be more appropriate to discuss the risk as it becomes relevant for each individual within the time-frame of PD treatment. A further complication is that there are still large gaps in the understanding of EPS, including the risk factors, but also delays in diagnosis and referral for surgical intervention (Augustine et al 2009). There is also some evidence that clinicians’
concerns about the risks associated with EPS are preventing them from suggesting PD therapy for patients (Brady and O'donoghue 2011, Summers et al 2011). This is particularly important in view of recent DH and NICE guidelines aimed at increasing the numbers of patients on PD nationwide (DH 2004, DH 2010a, Nice 2011).

Patients who develop EPS will have experienced dialysis and CKD over a number of years, and uniquely in the case of EPS they will have been undergoing self-care home treatment in the form of PD. The impact of CKD and dialysis has been described as catastrophic, due to the profound effect they can have on the physical, psychological and social aspects of an individual’s life (Allen Furr 1998). How patients cope and adapt to the negative effects has given increasing concern over a number of years, both to nurses and to healthcare professionals as a whole.

The overall concept of the present project has relevance with a long-term condition and the fact that the incidence of EPS is an acute life-changing event. The study is therefore intended to make a contribution to the knowledge surrounding CKD, and in particular how patients who have suffered CKD over a number of years cope with a new life-threatening disease.

1.1 Chronic kidney disease

Chronic kidney disease (CKD) is an irreversible process and if left untreated will cause death. It involves five stages (Renal Association 2009):

- **Stage 1**: Normal kidney function with structural changes, e.g. proteinuria;
- **Stage 2**: Mildly reduced kidney function
- **Stage 3**: Moderately reduced kidney function
- **Stage 4**: Severely reduced kidney function
- **Stage 5**: Very severe or end-stage renal disease
The terms used to describe CKD include end-stage renal disease (ESRD), end-stage renal failure (ESRF) or chronic renal failure (CRF). Referral to specialist nephrology services occurs at Stage 3 and later. By Stage 4 most patients are closely monitored and will begin the process of education, choice, planning, and preparation for dialysis, if that is their wish.

Renal Registry data give an indication of the growth in the number of patients with renal disease known to renal services. In 1982 the annual acceptance rate was 20 pmp (patients per million population), but by the end of 2008 the acceptance rate was on average 109 pmp (Renal Association 2009). The average acceptance rate has reached a plateau during the past three years. The estimate of people on dialysis in 2008 was 47,525, showing a growth of 4.4% from previous years. This growth was due to a number of factors, including greater awareness and detection in primary care, but also from the incidence of other conditions such as diabetes, which is the most common cause of renal disease and accounts for 25% of renal patients (Renal Association 2009).

1.1.1 Treatment possibilities

The trajectory of treatment for individuals with CKD is best described using the integrated care concept. Figure 1 demonstrates the cyclical pathway patients may undergo.

This concept illustrates the three main treatments used for CKD, which are haemodialysis, peritoneal dialysis and transplantation, collectively known as renal replacement therapies (RRT).

A further possibility is that a patient may choose conservative management. This is the conscious decision not to undergo dialysis but to continue to be monitored and managed by specialist renal services (Chandna et al 2011). This is not included in Figure 1.
In principle, dialysis is a treatment designed to filter the blood to remove toxins and waste products, which is normally a function of the kidneys. Fluid balance can be achieved using dialysis but individuals will still be subject to restrictions in diet and fluid intake, along with the medications required. It should be remembered that dialysis can only carry out a small percentage of the functions of a normal kidney.

In terms of treatment options there have been many changes over the years, mainly the result of advances in technology. Forty years ago few patients with kidney disease were offered dialysis – and they simply died. The 1980s and 1990s saw a vast growth in the availability of dialysis. Kidney transplantation may be the “gold standard”, but it is not available to everyone; there is a lack of donors nationally and many patients have to wait several years for a transplant (Bowman et al 2011). There are two main types of dialysis which will be described below.
1.2.1 Haemodialysis (HD)

Haemodialysis patients on average undergo treatment three or four times weekly for four to six hours; during this time the patient is connected to a dialysis machine. For HD to take effect patients must be provided with vascular access, usually by means of a fistula in the arm, or in some cases a semi-permanent catheter into a neck vein. The majority of patients undergo their dialysis in-centre, either in a main unit or a satellite unit close to home. In some centres, there is a growing number of patients undergoing HD at home, but currently these account for only 1-2% of the total dialysis population (Renal Association 2009).

1.2.2 Peritoneal dialysis (PD)

Peritoneal dialysis (PD) was fully introduced during the 1980s and saw a vast growth during that time, probably reaching a peak towards the end of the 1990s. PD involves provision of access into the abdomen by means of a catheter, through which the dialysis fluid can be introduced and withdrawn once dialysis is complete. Dialysis takes place using the peritoneum as a semi permeable membrane, which allows impurities to pass into the dialysis fluid before it is withdrawn and discarded. Figure 2 illustrates the location of the PD catheter. Figure 2
There are two types of PD. The first, introduced in the 1970s, is a manual procedure in which the patient performs dialysis exchange four times daily and is known as continuous ambulatory peritoneal dialysis (CAPD). The other type, introduced in the 1990s, is automated peritoneal dialysis (APD). APD takes place overnight while the patient is asleep. Patients are now offered a choice between the two techniques, and over the last 5-10 years the growth of APD has been considerable (Apostoula and Gokal 2000).

PD is a self-care therapy and can be managed by the patient and his/her family or carer at home. Before 2000 the majority of patients in the UK undertook dialysis at home – using HD in the 1970s and early 80s and PD from the late 80s onwards. Since around 2000, however, the number of patients on home dialysis has declined, and only 1-2% of dialysis patients now undergo haemodialysis at home. The number of patients starting on PD has declined from 40% in 2000 to 18.9% in 2008 (Renal Association 2009). Furthermore, there is considerable variation within the UK, many units having no or very few patients on home HD and fewer than 10% on PD (Brown et al 2009a). A similar spectrum of home dialysis treatments is also found in other countries, and the national and international differences in the prevalence of home dialysis cannot be ascribed to patient case mix (Murtagh et al 2008).

The decline in PD is common to most Western countries. A number of reasons have been suggested, including lack of patient education, physician bias, whether trainee nephrologists have been exposed to peritoneal dialysis, the belief that older patients cannot cope with home treatment, and the increasing numbers of frail elderly patients who would require assistance from family or community-based healthcare workers (Mehrotra et al 2005, Oliver and Quinn 2008). More recently, the risk of EPS has been suggested as a reason for the decline (Brady and O’donoghue 2011, Summers et al 2011). It is also important to consider the growth in numbers of patients who opt not to dialyse; as they previously may have gone onto PD (Chandna et al 2011).

The characteristics of patients who choose home dialysis have also been reviewed, particularly in the USA. It has been found that a typical PD patient tends to be an older male or a younger female,

- of white race,
married rather than living alone,
• having fewer pre-existing medical conditions,
• more likely to have received advanced education,
• be physically dependent,
• seen by nephrologists at an early stage, and
• autonomous in decision-making.

All of these studies are from the USA and therefore do not necessarily reflect the situation in the UK. The general consensus is that PD therapy is more common in the younger age group and this is confirmed in studies that demonstrate the reasons given by patients for choosing PD. A review of patients views taken from a cohort of patients on HD, PD and transplantation by Morton et al (2010) showed that home dialysis was chosen on the basis of lifestyle characteristics such as freedom, ability to work and independence (Morton et al 2010).

The elderly population is still a growing concern. By the end of 2008 the average age for starting dialysis in the UK was 65 (Renal Registry 2009), in the USA the fastest growing dialysis population was between 65-74 years (Finkelstein et al 2008a). The NECOSAD (2004) study from the Netherlands demonstrated that people over the age of 75 were six times more likely to choose HD. The implications of this are an increasing population of elderly patients undergoing HD. The situation is further compounded by the economic need to fill haemodialysis places once a unit exists – particularly in the private health area.

While the elderly are traditionally regarded as preferring HD for medical reasons, this conclusion is now being challenged, since it may merely be that PD carried out at home is more convenient. This group of patients is very important, and the required planning, support and education needs to be carefully considered. On the continent of Europe assisted APD has been developed to enable elderly patients to be treated at home by providing healthcare assistants to help them (Povlsen and Ivarsen 2005). Assisted PD programs for the elderly have shown benefits in Europe and Canada (Oliver et al 2007, Polvsen and Ivarsen 2007) and are now being used in the UK (Hurst and Manley 2010).
Studies examining the impact of education on choice demonstrate that usually 50% of patients chose home based therapies when provided with good education over a period of time (Golper 2001, Necosad 2004, Goovaerts et al 2005, Manns et al 2005, Oliver et al 2007, Oliver and Quinn 2008, Brown et al 2010). Many of the barriers to home dialysis are apparent rather than real and there are few true contra-indications (Brady and O’donoghue 2011). Barriers as perceived by patients has been shown to be predominantly related to disinterest by patients and families, lack of social support and communication (Visaya 2010, Zhang et al 2010).

PD has received renewed attention during the past five years, as has the issue of patient choice, in an attempt to try and reverse the current trends. Publications such as the National Service Framework and various Department of Health documents are aimed at improving patient choice, enhancing self-care and listening to patients’ experiences (DH 2001, DH 2004, DH 2005b, DH 2005a, DH 2010a). A recent NICE (2011) guideline, intended to provide patients with informed choice and promoting PD as a suitable home therapy, should see an increase in PD numbers in the UK. Self-care strategies and expert patient programmes have been published by the DH (DH 2001, DH 2007) and developed for a range of long term conditions. As a result, the benefits of home dialysis and the need to improve the uptake of PD have been described as “an essential and central theme of delivering modern renal services” (Brady and O’Donoghue 2011).

An additional driving force is the current financial situation within the NHS in the UK and the emphasis on delivering cost-effective high quality care (Nice 2011). PD has traditionally been a less costly option (Gokal et al 2000), and the need is therefore to focus on patient preferences, perceived clinical benefits and ultimately to demonstrate an increase in PD. This will offer cost savings without compromising patient choice.

The relevance of these factors to the present study is how and at which stage EPS is discussed with patients, and secondly, how patients perceive the information requirements particularly, transitions between PD and HD.
1.2.3 Survival and outcomes in dialysis

Since the introduction of PD a number of studies have compared the respective survival outcomes of PD and HD, including large registry-based studies in the USA, Europe and Australia (NICE 2011). Criticisms of these studies have in the main been directed towards factors such as differences in case mix, but additional factors such as social support and quality of life (QOL) have not been adequately considered (Renal Association 2009). The debate continues about the merits of PD compared with HD, but recent reviews suggest that within the first two years there are no significant differences (Vonesh et al 2006, Vale et al 2009). The two therapies are in effect complementary, since most CKD patients will at some stage have experienced both HD and PD (Blake 2001).

It is now being appreciated that PD is not in fact a long-term therapy, and although it has a very important role in the management of CKD, it has a limited lifespan as a technique. With regard to duration of the technique, the rate at which patients come off PD in the UK is quoted as 50% after two years (Tangri et al 2008). The rate of technique survival on PD is often the reason for not offering PD to patients, since the therapy may be considered doomed to fail. There are, however, a range of potential factors leading to the failure of PD, including peritonitis, membrane failure, inadequate dialysis, a change in social circumstances leading to insufficient support, or that patients no longer feel able to cope with PD at home. The term “failure” is therefore misleading, and the reasons given previously for the drive to increase the uptake of PD are now at the forefront. Other reasons patients come off PD are transplantation and given the growth of kidney transplants, especially living related in the last 10 years it is not surprising PD numbers have declined. By 2003 1,409 kidney transplants had been done in the UK, of which 376 were living related; by end of March 2011 a total of 2,732 kidney transplants had been done of which 1,045 were living related (NHS 2011).

The aim is for younger patients to start on PD, with anticipation of transplantation within three years (NICE 2011). The reasons PD is advocated as a good first line treatment are not only patient choice but also it will preserve the need for vascular access and there is some evidence of preservation of residual renal function (NICE 2011).
There are differences to consider with different age groups and those with existing co-morbidities. In the UK life expectancy of CKD patients on dialysis over the age of 75 averages at two years (Renal Registry 2009), therefore their needs are different, transplantation is not an option and longevity is not necessarily the primary objective. The choice between dialysis or conservative management must clearly be patient-focused, and matters such quality of life and informed patient decision making included (Kelly-Powell 1997, Tweed and Ceaser 2005, Morton et al 2010).

End of life care is also becoming a major focus for patients with CKD, in particular for the elderly and those with multiple co-morbidities, and UK-wide projects have been developed to address the management and needs of this group (DH 2005b). A supportive care model has been proposed as a means of changing the focus of care delivery, including advanced care planning (Davison and Simpson 2006). The illness trajectory of CKD should be recognised as including acute events, rapid decline during the advanced stage and the possibility of sudden death (Murtagh et al 2008). Reported survival outcomes in the elderly with co-morbidities opting for conservative management are comparable to outcomes for those opting for dialysis, indicating the need for careful information, education and support in this group (Chandna et al 2011).

1.2.4 Complications of dialysis

Dialysis brings with it a number of complications. In PD the most common of these is peritonitis, which in most instances is readily treatable and does not require hospital admission (Gokal et al 2000). Infection is also common in patients on HD, arising from catheter sites and fistulas. Patients using each of these therapies can have what are described as “access” problems, relating to the catheter in PD or the fistula in HD. Infection often requires surgical or radiological intervention and can be very unpleasant for the patient.

Cardiovascular disease is common in all patients with CKD, and the risk of myocardial infarction and strokes is also increased in this group of patients (Nolan 2005). It is now widely accepted that the largest survival risk factor in dialysis populations is cardiovascular disease (Khan 2000, Nolan 2005). Other complications directly related to
dialysis are bone disease and the development of renal osteodystrophy. Patients with other co-morbid conditions, such as diabetes, also have complex needs that must be considered (Khan 2000, Sekkarie and Swartz 2004).

EPS is a rare complication, but one directly linked to PD, and forms the focus of the present study. Patients at risk of EPS will have survived all the possibilities of technique failure or other co-morbid conditions. This aspect will discussed in detail later in this chapter.

1.3 Impact of chronic kidney disease and dialysis

The impact of renal disease is physical, psychological and social, features common to many other long-term conditions. CKD does, however, have certain unique aspects relating to the technology involved in the treatment and the restrictions imposed by diet, fluid intake and medication.

The physical symptoms have been reported in many studies and include fatigue, pain, sleeplessness, itchiness and a general reduction in physical activity (Murtagh et al 2007). Psychological symptoms include stress, anxiety and depression (Kimmel 2005, Lew and Piraino 2005, Finkelstein et al 2008b). Coping and adaptive behaviours are complex and are integral. Differences can be detected between those patients who choose different modalities, for example between home and in-centre treatments. Some studies indicate that patients on PD tend to be younger, healthier and more privileged (Diaz-Buxo et al 2000, Wu et al 2004).

Comparisons have been made in an attempt to demonstrate whether one treatment provides a better quality of life (QOL) than another, without the influence of individual preferences (Wu et al 2004). The overall conclusions from reviews of QOL have shown that transplant patients tend to have a better overall QOL, that PD patients show more favourable adjustment than HD patients, and that physical symptoms are often the result of anxiety and depression (Bowman and Martin 1999, Liem et al 2007).

The social effects of CKD include relationships, roles and activities, and the financial issues arising from loss of employment. The world of a dialysis patient can be isolated
and social activities are greatly reduced (Faber et al 2003). Sexual and body image problems may arise and are often poorly understood (Muringai et al 2008). The impact of the disease on the family is also very important to consider and some studies have focused in particular on this (Soskoline and Kaplan-De-Nour 1989, Brunier and Mckeever 1993, Courts and Boyette 1998, Lindqvist et al 2000, Suet-Ching Luk 2002, Belasco et al 2006, Turkinaz et al 2006, Fan et al 2008). The effects on the family varied between modalities and were often dependent on culture, age and economic factors highlighting the need to consider the family and carers as part of the care and support required by individuals on dialysis.

Depression is a common psychological problem within the dialysis population and its diagnosis can be difficult (Kimmel 2002, Tossani et al 2005). Depression is linked to increased hospitalisation and other complications, including mortality, and has given rise to considerable concern (Kimmel 2002, Einwohner et al 2004, Lew and Piraino 2005, Finkelstein et al 2008b). There are also correlations between physiological stresses and the severity of anxiety symptoms, depression and social support (Lew and Piraino 2005, Ye et al 2008). Other studies have shown that perception of illness correlates with depression rather than clinical indices (Sacks et al 1990, Cristovao 1999), which are arguably more important than QOL scores (Kimmel et al 2003). Some studies have also compared coping strategies and QOL and have shown that problem solving and optimistic methods work better for the majority of patients rather than emotive coping (Smith Baldree et al 1981, Prater 1985, Lok 1996, Lindqvist and Sjoden 1998, Cristovao 1999).

Measurement of QOL does however have a role in clinical practice, provided agreement can be reached about accurate tools and that the results are used appropriately. However, a holistic approach to patient management based on individual patient needs can only be understood if the patient perspective is taken into account. As such, qualitative assessment of the experience can provide an insider’s view of the illness and the coping strategies employed by patients (Thorne 1999). Outcomes reported by patients can be as important as clinical outcomes, particularly in CKD, and routine practice should therefore aim to capture and listen accurately to patients’ experience.
Within the perspective of EPS, this background information provides an insight into what patients have to tolerate during CKD and in living with dialysis. This information provides a clear context for the patients to be included in this study. The potential rise in PD numbers is also an important consideration, and its influence on clinical practice must be assessed; being able to provide accurate information to guide informed decision making will also be essential. The spectre of EPS has been suggested as a possible reason for not offering PD, therefore an insight into the views of patients who have had EPS may guide clinicians and lead them to a less negative outlook.

Initially, however, an overview of EPS will be given, along with current prevalence and incidence rates, diagnostic criteria, risk factors and views arising from current clinical research.

1.4 Encapsulating peritoneal sclerosis (EPS)

Encapsulating peritoneal sclerosis (EPS) is an uncommon but serious complication of long-term PD. The reasons why EPS occurs are still not fully understood. A number of hypotheses have been advanced relating to injury to the peritoneum, including genetic predisposition (Kawaguchi et al. 2000). The process of fibrosis which takes place in EPS can happen with all PD patients, but the development of an additional adhesion process is believed to occur in EPS. The reason for this is still not yet understood and is sometimes described as a “second hit” to the peritoneum (Kawaguchi and Tranaeus 2005). EPS is characterised by bowel obstruction and marked sclerotic thickening of the peritoneal membrane (Brown et al. 2009b).

Various terms have previously been used for the condition, but the term “encapsulating peritoneal sclerosis” best describes the morphological process, in which acute inflammation or peritonitis may be absent during later stages of the condition (Kawaguchi and Tranaeus 2005). The number of publications on EPS has increased significantly over the last 10 years (Kawaguchi and Tranaeus 2005). Most of these have originated in Japan, where the majority of guidelines for the management of EPS have originated (Kawaguchi et al. 2005). However, PD practice in Japan differs from that in the UK, in that the availability of renal transplantation is very limited and
patients tend to remain on PD longer, leading to a greater incidence of complications associated with long-term PD, including EPS.

1.4.1 Diagnosis

EPS is often described as the most serious complication of PD. As Kawaguchi asserts, “After more than 25 years’ experience of PD, PD-related EPS ought to be considered an iatrogenic morbidity” (Kawaguchi and Tranaeus 2005). Patients who experience EPS may have had symptoms for several months, in many cases undetected. The criteria initially recommended by ISPD (2000) has been updated by Nakamota (2005), and more recently described by ISPD in a position paper (Brown et al 2009b).

The initial suspicion usually arises from signs of bowel obstruction and features of encapsulation. Earlier indications of anorexia, weight loss, abdominal distension, bowel disturbances and vomiting are all common. When obstruction occurs it usually points to EPS, but it can only be confirmed by computerised tomography (CT) or laparotomy. Other indications are given by biochemical parameters, such as bloody PD effluent, hypo-albuminaemia, anaemia, and raised C-reactive protein (Nakamoto 2005, Brown et al 2009b).

Close monitoring of long-term PD patients for these symptoms is now recommended (Renal Association 2009). Referral to a specialist surgeon is recommended without delay. Only two centres in the UK offer this specialist surgery, located in Manchester or Cambridge.

1.4.2 Incidence

Reported incidence of EPS varies, as illustrated in Table 1.
Table 1: Studies of incidence of EPS

<table>
<thead>
<tr>
<th>Author, year and locality</th>
<th>Total PD patient numbers</th>
<th>Total EPS cases</th>
<th>Overall incidence</th>
<th>Cumulative incidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>*(Rigby and Hawley 1998)</td>
<td>7374</td>
<td>54</td>
<td>0.7 %</td>
<td>1.9% &gt; 2 years</td>
</tr>
<tr>
<td>(Australia) multi-centre</td>
<td></td>
<td></td>
<td></td>
<td>6.4% &gt; 5 years</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>10.4% &gt; 6 years</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>19.4% &gt; 10 years</td>
</tr>
<tr>
<td>*(Nakamoto et al 2002)</td>
<td>11 549</td>
<td>256</td>
<td>2.2%</td>
<td></td>
</tr>
<tr>
<td>(Japan) multi-centre</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>*(Summers et al 2005)</td>
<td>810</td>
<td>27</td>
<td>3.3%</td>
<td></td>
</tr>
<tr>
<td>(UK) single centre</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>*(Kawanishi et al 2004)</td>
<td>1958</td>
<td>48</td>
<td>2.5%</td>
<td>5.9% &gt; 8 years</td>
</tr>
<tr>
<td>(Japan) multi-centre</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>*(Brown et al 2009c)</td>
<td>1238</td>
<td>46</td>
<td>2.8%</td>
<td>8.1% &gt; 4 years</td>
</tr>
<tr>
<td>(Scottish renal registry)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>*(Johnson et al 2010)</td>
<td>7618</td>
<td>33</td>
<td>0.4%</td>
<td>0.8% &gt; 5 years</td>
</tr>
<tr>
<td>(Australia/New Zealand)</td>
<td></td>
<td></td>
<td></td>
<td>3.9% &gt; 8 years</td>
</tr>
<tr>
<td>*(Bansai et al 2010)</td>
<td>676</td>
<td></td>
<td>1.2%</td>
<td>15% &gt; 6 years</td>
</tr>
<tr>
<td>(USA) registry case</td>
<td></td>
<td>61</td>
<td></td>
<td></td>
</tr>
<tr>
<td>controlled</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>*(Korte et al 2009)</td>
<td>2022</td>
<td></td>
<td>2.7%</td>
<td>After transplantation, risk increased to 7.5%</td>
</tr>
<tr>
<td>(Dutch registry)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>retrospective case</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>controlled</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Studies employing the ISPD criteria for diagnosis (Kawaguchi et al 2000).
A further study, of cases in the Pan-Thames area, has not been included as overall incidence was not published. Mortality was the reported outcome and identified that of the 111 reported cases over a seven year period, 71% had been on PD for > five years (Balasubramaniam et al 2009). Variation in incidence may possibly be related to differences in PD practice, diagnostic criteria and racial or genetic factors. Due to the relative rarity of the condition there are limitations both in our knowledge and in the current literature with regard to clinical aspects, including epidemiology, diagnosis, and particularly its management (Summers et al 2011). There is also a growing concern regarding the number of reported cases post-kidney transplant (Summers et al 2011). It is possible that a greater awareness of the condition is leading to increased diagnosis of milder cases – or it could be that EPS is becoming more common (Wilkie 2011).

1.4.3 Risk factors

In current PD practice the significant risk factors for the development of EPS include the duration of PD, possibly the use of hypertonic glucose dialysate and evidence of membrane failure (Kawaguchi and Tranaeus 2005, Kawanishi and Moriishi 2005, Brown et al 2009c, Bansai et al 2010, Habib et al 2010, Korte et al 2011). The incidence of EPS increases with duration of PD (Table 1). On the other hand, a significant proportion of cases of EPS developed after PD has been discontinued (Nakamoto 2005), following transfer to haemodialysis, or after renal transplantation. However there is no current evidence that stopping PD was a cause of EPS, in fact some studies indicate that it was likely that early signs of EPS were present before the switch to HD (Korte et al 2009, Habib et al 2010, Korte et al 2011). In one report from Australia and New Zealand all the cases were diagnosed while undergoing PD, but the paper does not state the criteria used for diagnosis (Johnson et al 2010). Some studies demonstrate a greater incidence of EPS in younger patients (Habib et al 2010, Johnson et al 2010) and there is speculation that increased exposure to large dialysate volumes, as seen in APD and icodextrin solutions, maybe a risk factor (Habib et al 2010, Korte et al 2011). However, it has been pointed out by Wilkie (2011) that it is difficult to draw conclusions from these studies because it is known that in membrane failure
(ultrafiltration failure) larger volumes, with greater glucose and icodextrin exposure, are used. The primary risk is therefore membrane failure rather than exposure to these higher concentrations:

*Investigations of EPS are challenging for several reasons, including rarity of the condition, the fact that it may take several months before diagnosis is made and the paradox that EPS is a “condition of survivors”.* (Wilkie 2011)

EPS is an important condition, since it can result in prolonged debilitating illness. As has been mentioned, it may be a significant barrier to long-term PD treatment and it seems to have a disproportionately negative impact on clinicians’ perception of PD as a therapy for ESRD, compared with equally frequent and more severe therapy-specific complications in haemodialysis. The following factors have been recommended by ISPD in considering the risks mentioned:

1. *Age and prognosis of patient;*
2. *Length of time on PD, especially total glucose load and history of peritoneal infections;*
3. *Access to and suitability for transplantation;*
4. *Potential risk of HD in this particular patient (hemodynamic stability, vascular access); and*
5. *Quality of life of the patient.*

*All these items should be discussed and any decision should be agreed with the patient.*

(Brown et al 2009b)

### 1.4.4 Treatment and management

The treatment and management of EPS remains difficult and contentious. Pharmacological treatments have been reported only in a small number of cases and little evidence can be deduced about their effectiveness (Brown et al 2009b). There tends to be an emphasis on nutritional management and support, since this is effective in allowing the bowel to rest, but currently there are no publications which demonstrate whether this treatment is preferable to surgery. It is however an essential
preoperative requirement for patients about to undergo surgery, since the majority of patients presenting tend to be malnourished (De Freitas et al 2008).

Experiences of surgical treatment in Japan have been published, including extensive surgery to treat encapsulation and bowel obstruction. One report of 50 patients showed 4% postoperative mortality and 96% survival after three years (Kawanishi et al 2005), a significant improvement over previously published historical studies indicating high mortality (Nomoto et al 1996, Rigby and Hawley 1998). More recently, studies reporting incidence of EPS using case control matches have found no difference in mortality in patients on PD with or without EPS, but in many cases co-morbidities are not given for either group (Korte et al 2009, Johnson et al 2010).

A UK initiative in Manchester and Cambridge has secured funding through National Specialist Commissioning Advisory Group (NSCAG) to provide specialist surgery for patients in the UK, and publication of outcome data is currently in progress. The experience within Manchester is growing and will be a factor in the future care and management of this group of patients.

It is quite clear that EPS places an immense physical burden on a patient who is already undergoing dialysis. The surgery itself is long, and patients postoperatively usually spend two or three days in intensive care and require a high level of nursing care during this time. If complications occur the wound is left open and the patient may have to return to theatre a number of times, or even be left with a temporary stoma (the bowel brought out of the abdomen). A crucial aspect is nutritional support and allowing sufficient time for the patient to resume a normal eating routine. A number of specialist teams are becoming involved in the care of these patients (Augustine et al 2009). Another important aspect is the switch of modality that patients undergo during this period, since if they are diagnosed while on PD they will be automatically switched to HD therapy. Patients may have only been on HD for a few months before diagnosis, which involves a number of complex changes to an individual patient over a short space of time.

Research into EPS has primarily focused on genetics and patho-physiological surgical treatments and outcomes (Schmidt and Flessner 2008). Collaboration with European countries has now been agreed in order to improve data collection, and to establish
clinical and laboratory projects to establish the clinical and biological risk factors for EPS (Summers et al 2011). While these are all extremely important in striving to understand and improve patient care, the social and psychological aspects must not be ignored. With this in mind, the focus of the literature review will be a review of CKD and dialysis and its impact. This provides the context for the present study, since patients who develop EPS have naturally all been on dialysis. It also important to establish the views of patients on their experience of EPS, its impact on their lives and what we can learn from these experiences in terms of the delivery of information and care.
Chapter 2: Literature Review

2.1 Introduction

The focus of the present study has been to explore the experiences of patients diagnosed with EPS. All of these patients will have experienced dialysis and now find themselves having to come to terms with a life-changing and potentially life-threatening disease.

The purpose of this literature review is to provide an overview of previous research in this area of study. A traditional review concentrates on a broad overview of the literature, noting the strengths and weaknesses of studies, but is described more specifically as critical (Wallace and Wray 2011). For this study it was important to present a constructive critical account of published research, highlighting gaps in knowledge as well as the current available evidence. However, since there have been no previous studies directly concerned with patients’ experience of EPS itself, a decision was taken to review the broader literature concerning patients on dialysis. This is appropriate in that studies which have explored the experiences of living on dialysis can provide a context for the current study and help to clarify the theoretical consideration. The review was focused on studies that explored experiences of patients on dialysis, as these were most pertinent to the topic being studied. Although no specific questions were set for the review, research that aimed to explore experience, meaning or perspectives of patients were included. The literature search focused on identifying studies which presented the voice of the patients themselves and their individual perspectives.

2.2 Search strategy

The search strategy is a key component of the literature review. One of the criticisms of narrative reviews is the lack of transparency in the literature search (Wallace and Wray 2011). To ensure all relevant literature has been sourced a systematic approach
to searching was employed. This should avoid bias, but with all literature searches there are limitations (Briggs 2008, C.R.D 2008). The approach and search terms used are described below.

2.2.1 Inclusion criteria

- Studies published between 1985 and April 2011;

- Experiences of dialysis from the patient perspective;

- Single or combined renal replacement experiences, including in-centre haemodialysis and also home and peritoneal dialysis; and

- Studies and reviews of the meaning of illness in dialysis and CKD.

2.2.2 Exclusion criteria

- Studies related to patients younger than 18 years of age;

- Studies of transplant patients’ experiences alone;

- Exclusively studies of family and care givers’ experiences; and

- Non-English papers.

2.2.3 Search terms

Broad terms – Dialysis, chronic kidney disease, renal failure, renal replacement therapies. These terms yielded over 11,000 hits and so further combined specific terms were necessary to give focus to the search.
Specific terms – Peritoneal dialysis, haemodialysis, experiences of living on dialysis, meaning, coping and adaptation, perceptions of dialysis. Encapsulating peritoneal sclerosis was included as a separate search employing the search terms above.

2.2.4 Sources

The databases chosen were specific to include nursing, medical and social science literature.

**Databases:**

- ASSIA
- CINAHL/EBSCO
- British Nursing Index
- Embase
- Psychinfo
- Social policy and practice
- Health and psychosocial instruments
- Medline.

2.2.5 Hand searching

A hand search of journals was not conducted for the present review due to the diversity of locations in which studies were published. However hand searching of bibliographies of books and papers retrieved was helpful in locating previous studies and was employed in the search.
2.2.6 Grey literature

This term describes literature that at present remains unpublished. Identifying unpublished research is clearly important although very difficult to achieve. Searching thesis databases for authors working in the area was employed.

2.3 Results of literature search

The majority of the articles, a total of thirteen, were retrieved from EBSCO and eight were recovered from the other databases. Hand searching of bibliographies yielded a further eight studies. Theses and dissertations are listed in some databases; one of the studies retrieved was a dissertation and was found in EBSCO. This study was however excluded since only an abstract was provided and the full thesis was not obtainable. The thesis database was also searched separately but no relevant studies were found.

2.3.1 Studies included

A total of 28 studies and one literature review were identified. A summary of the included studies is provided Appendix 1. None of the studies revealed any experiences or psychological aspects of EPS. The studies in the present review are predominantly qualitative; this was not intentional and is not regarded as a limitation to the literature review. Search terms and strategy focusing on “experiences” and “meaning” of living on dialysis confirm that research questions and subjects of this origin inevitably generate qualitative studies.

The studies included varied in their aims but generally set out to understand the perceptions, meanings and experiences of patients with CKD undergoing dialysis.

Three authors have published more than one study in this area (Hagren et al 2001, Curtin et al 2002, Polaschek 2003b, Curtin et al 2004, Hagren et al 2005, Polaschek 2007). Background details of authors were not always revealed, but it is estimated that the majority were nurses, and three of the studies were clearly carried out from a sociological perspective (Kutner 1987, Gerhardt 1990, Faber et al 2003). Two publications were clearly the same study (Moran et al 2009b, Moran et al 2010) and so the results from both were used but classified as one study.
2.3.2 Participants and settings

All the studies set out to describe experiences and meaning of illness across the range of renal replacement therapies, including transplantation, but only as part of a combined study (appendix 1). Renal modality was used to describe unique groups, and two studies purposefully explored HHD experiences alone, eight combined different groups (appendix 1). PD was only discussed in nine of the studies, either as a combined treatment, or in two instances alone (appendix 1). The majority of studies of HD involved in-centre therapy. This is a reflection of the fact that in-centre dialysis is provided for the majority of patients throughout the world (appendix 1). Appendix 1 also indicates the origin of each study and the numbers of participants involved. There was also variance in representation of men and women, one study included only women (Tanyi and Werner 2008), one only men (Polaschek 2003b), the age ranges varied according to the renal modality so as would be expected more elderly patients on hospital HD. Cultural and ethnic differences were not described well other than often a reference to Caucasian indicating a white background.

2.3.3 Methods

The methods used in these studies, with one exception (Caress et al 2001), were entirely qualitative. All the qualitative studies used interviews, with variations in the details given. Some interviews were semi-structured, and examples of questions are given; others were open-ended. Certain studies involved more than one interview, and in some of them no indication of the questions or topics was given. Most studies contained details of the time spent interviewing and the transcription process. Some involved observation, diaries and reflective accounts by the authors as part of the methodology.

There was variance in the description and underpinning philosophy of the studies. Some were very clear and followed a particular theory through to the analytical process, providing clarity and implying trustworthiness in the data (Kutner 1987, Gerhardt 1990, Rittman et al 1993, Gregory et al 1998, Caress et al 2001, Kierans and Maynooth 2001, Curtin et al 2002, Walton 2002, Faber et al 2003, Martin-McDonald
2003, Curtin et al 2004, Dekkers et al 2005, Giles 2005, Hagren et al 2005, Ravenscroft 2005, Kaba et al 2007, Molzahn et al 2008, Tanyi and Werner 2008, Moran et al 2009b, Moran et al 2010). Seven studies used phenomenology, of which four used hermeneutics; one interpretive phenomenological analysis and two descriptive phenomenology with bracketing, but only one of these provided details of bracketing and reflexivity within the study (appendix 1). Four studies used grounded theory (Gregory et al 1998, Walton 2002, Faber et al 2003, Kaba et al 2007). Many studies gave only a broad description of an exploratory qualitative study and details of analysis by coding and themes. Some of the studies may have been influenced by the policy of the journal and the space allocated, as differences in depth and detail appeared to be a feature of the journal concerned. Contacting the authors for further details was not practicable.

2.3.4 Quality of studies

The assessment criteria for qualitative research have been developed in parallel with criteria for quantitative studies in an effort to satisfy the demand for evidence-based practice. This has led to an increase in the number of systematic reviews and the hierarchy of evidence, which is fundamental to the production of evidence-based medicine in healthcare. Since the majority of papers in the present review were qualitative, it was important to consider methods of appraisal. The criterion of qualitative work is that it will be judged against randomised control trials (RCTs) as the gold standard (Popay et al 1998).

There are gaps in the literature regarding the way qualitative research is appraised on the basis of its subjective methods. However, there is increasing agreement that qualitative research will increase and broaden the knowledge required for evidence-based practice.

Methods of assessing qualitative work have aroused considerable debate (Sandelowski 1986, Sandelowski 1993, Popay et al 1998, Rolfe 2006, Porter 2007). Some of the debate relates to problems arising from three different factors, firstly, the need to use similar criteria to those applied in quantitative research, secondly, to develop a new set of criteria and, thirdly, to have no predetermined set of criteria (Rolfe 2006). Frameworks have been published on assessment criteria with very similar content.
Miles and Huberman 1994, Popay et al 1998, Spencer et al 2003, Casp 2006, Briggs 2008). After assessing the contents of each of these articles, the framework identified by the Joanna Briggs Institute (JBI 2008) has been selected for reviewing the studies. The reason for this lies in the diversity of the methodological approaches used in the studies and the simplicity of the checklist in providing a framework to assess the studies. In appendix 1 only comments indicating weaknesses are listed; if no such comments are given this confirms that the study concerned fulfilled the criteria laid out by the Joanna Briggs Institute (pg 153 2008). Appendix 2 gives the actual checklist used.

One study (Bruno 1999) and one literature review (Polaschek 2003a) were excluded, leaving 27 studies. The reasons for exclusion were that the criteria described above were not met; the literature review by Polashek (2003a) did not clarify a strategy and at least a further nine studies were identified for this review before the Polaschk (2003a) publication.

2.3.5 Analysis and synthesis

There has been increasing discussion in the literature as to how the synthesis of qualitative studies can best be presented (Finfgeld 2003, Thorne et al 2004, Flemming 2007). The intention of the debate is to increase the knowledge base from nursing studies in line with evidence-based practice, which requires a shift from individual studies to a combination of these in order to construct and formulate theory. This can then perhaps influence healthcare professionals and make it possible to translate theory into practice. Meta-synthesis and meta-ethnography are two of the methods used to synthesise studies; however this approach requires expertise, time and a number of reviewers and is not recommended for novice researchers (Finfgeld 2003, Thorne et al 2004).

The diversity of the methods and groups of participants in the review give rise to some important questions as to how they should be presented. One way would be initially to examine the experiences of the HD groups, then the combined groups, and finally PD alone. However, following careful analysis of all the studies it became apparent that a number of common themes and concepts had emerged. The narrative will therefore
be presented in terms of the general themes and concepts derived from the studies included.

**2.4 Main Themes From Studies Reviewed**

For the literature review studies were examined individually, the findings tabulated and common themes identified. DeSantis (2000) provides a useful description of a theme (Desantis and Ugarrzi 2000):

*An abstract entity that brings meaning and identity to a recurrent experience and its variant manifestations. As such a theme captures and unifies the nature or basis of the experience into a meaningful whole.*

In addition to themes, concepts arising within the studies were also helpful to the process of evaluation. DeSantis has pointed out that concepts of categories, domains or taxonomy are examples of levels at which themes can emerge (Desantis and Ugarrzi 2000).

Ten themes were identified from all of the studies representing the major findings. These were:-

- Uncertainty
- Haemodialysis and the dialysis machine: Dependency Issues
- Normality and lifestyle
- Meaning of Illness
- Emotions
- Physical Effects
- Relationships: Families and healthcare providers
- Body Image
- Suffering
- Spirituality
2.4.1 Uncertainty

Uncertainty was a central theme to many of the studies (see table 2 appendix 1). One study examined what was described as “liminal spaces” experienced by people on dialysis (Molzahn et al 2008). Liminality was described by Molzahn et al. (2008) as the ‘in-between or ambiguous spaces’, associated in the literature with uncertainty. The Molzahn study used a narrative review of stories written by patients in a book, which makes it essentially a secondary analysis; this may have weakened the constructs as the authors had no access to the participants. Themes were developed based around patients on dialysis living in this liminal space while waiting for a transplant, similar to Moran’s second publication where uncertainty was a theme associated with waiting for a transplant, life was put on hold and so created uncertainty (Moran et al 2010). The themes described were defined around adaptation and the in-between situation felt by individuals. This gave a contrast between ‘normal’ and ‘not normal’, and being ‘independent’ but at the same time ‘dependent’. This was similar to Martin-McDonald (2003) who described continuum themes, meaning an individual struggles between being free and being restricted. From the other studies uncertainty was described in similar contexts, some more explicitly than others.

The concept of uncertainty was often described as being temporal, in other words it changes over time (Curtin et al 2002, Polaschek 2003b, Kaba et al 2007). Other studies described uncertainty when participants were in a situation of the “unknown”; this is referred to in a number of different contexts. Fear of death is an uncertainty that could arise at the beginning of dialysis once the diagnosis and prognosis are clear (Kutner 1987, King et al 2002, Walton 2002, Velez and Ramasco 2006). Molzahn’s (2008) study of the liminal space suggests that most qualitative studies of dialysis populations do not raise concerns about the threat to life, but a large proportion of them did in fact refer to the fear of death in one way or another, using expressions such as life being “on a thread” (Keeping et al 2001, King et al 2002, Curtin et al 2004). Death is described as being invariably an issue, constantly hanging over a patient (Keeping et al 2001, Curtin et al 2002, Curtin et al 2004, Dekkers et al 2005, Hagren et al 2005, Moran et al 2010). Witnessing other patients die serves to remind patients of their own mortality (Walton 2002, Curtin et al 2004). Kutner (1987) has described treatment as “borrowed time”, and that participants are conscious of how much time they may
have left; Keeping and English (2001) described it as living on the border between life and death.

Uncertainty is inevitably at the forefront of the patient’s mind during acute illness. Patients have to live with the uncertainty of not knowing when or whether something may go wrong, or with the possibility of debility as the illness advances (Kutner 1987, Gregory et al 1998, Keeping et al 2001, King et al 2002, Kaba et al 2007).

The emotional struggle patients had to endure in coping with uncertainty is argued to form part of the adaptive process (Gregory et al 1998, Tong et al 2009). This has at times been considered to be in conflict with the more optimistic view offered by healthcare professionals (Kutner 1987, Kaba et al 2007). Curtin (2002), whose study relates particularly to long-term survivors, has described the manner in which participants come to terms with uncertainty, adapting to it by living for today and not planning too far into the future.

This is also a feature of chronic uncertainty, which is often associated with increased depression and anxiety (Kutner 1987). Kutner (1987) and Gregory (1998) have described the uncertainty of patients’ choice of modality and its associated problems, for example doubt about whether to change renal replacement therapy (RRT) and not knowing if this will be of benefit. It is interesting to observe that in many cases patients are in fact prepared to change modality over the course of their illness, and little is mentioned of these transitional events in earlier studies.

However, none of the studies gave a great detail of attention to events that caused uncertainty or which gave meaning to these events, perhaps because the events during a person’s life on dialysis can present such different meanings. Curtin refers to setbacks and how some participants felt caught off-guard by certain complications – but they continued to struggle, readjust and move on (Curtin et al 2002). Hutchinson argues that more research is needed in patients with ESRD, specifically addressing the aspects of uncertainty that may be triggered in times of crisis and transition (Hutchinson 2005).
2.4.1.1 Risk and Decision Making

There is a large volume of literature which focuses on such aspects as shared decision-making, communication of risk and information-giving in healthcare, and indeed there have been several Cochrane reviews in these areas (Akl et al 2010, Stacey et al 2010, Legare et al 2011). The present literature review specifically addressed experiences of dialysis and did not extend to studies which focused primarily on decision making or giving prognostic information. Nonetheless, these issues were apparent in some of the papers reviewed, specifically regarding communication of uncertainty, information gaps, ambiguous diagnosis and aspects of decision making. As most of the studies represent the voice of the participants’, specifics of risk information, prognosis and decision making are not described in detail. Shared decision making has been described widely as an important component of the relationship between HCP’s and patients and was an aspect of some of these studies (Gregory et al 1998, Walton 2002, Curtin et al 2004, Ravenscroft 2005, Kaba et al 2007). It related to the ongoing management and negotiation that the patients felt was important. EPS poses a challenge as an important risk factor for patients on PD and how it is communicated as a risk was not included in these studies. Michel and Moss (2005) describe the difficulties but also the relevance of sharing information about dialysis, stating ‘disclose all information about the medical condition including risks, benefits, and consequences of all available treatments as well as consequences of no treatment’ (Michel and Moss 2005).

2.4.2 Haemodialysis and the dialysis machine: Dependency issues

Patients on HD often refer to the impact of the machine and how it tends to dominate their whole experience (Walton 2002, Polaschek 2003b, Dekkers et al 2005, Kaba et al 2007, Moran et al 2009b). The machine is also seen to be controlling the body, and the body being separated from the self, with the feeling that the patient has lost control over it (Rittman et al 1993, Giles 2003, Giles 2005, Velez and Ramasco 2006). On the other hand, the machine may paradoxically in many cases be seen as a lifeline with the purpose of sustaining life (Hagren et al 2001, Curtin et al 2002, Faber et al 2003, Hagren et al 2005). Patients therefore regard it as crucial to keep the same machine, since they look upon it as part of them and their lives. Walton (2002) and Curtin (2002)
have described acceptance of the life-saving aspects of the machine as a reframing and adaptation experience, but in addition allowing the patient some control over the treatment. Polaschek (2003) refers to this as an interrelationship between dependence and autonomy. The symbolism of the machine generating dependency is reflected in some participants’ view of the entire illness as being a dependent process, leading to a struggle between dependence and independence (Kaba et al 2007, Molzahn et al 2008).

The time spent on the dialysis machine has been considered in a number of studies (Rittman et al 1993, Hagren et al 2001, Ravenscroft 2005, Moran et al 2009b). In essence, how patients adapt to the machine and cope with it is somewhat variable, some studies expressing dialysis in terms of “work” or a “career” (Kutner 1987, Gerhardt 1990, Faber et al 2003). The study by Faber (2003) has adopted work as the main theme, as patients attempt to cope with the limitations imposed by dialysis. In Moran’s study time was described as ‘killing time’ and ‘waiting time’, both related to individuals perceptions of how much time is taken waiting to go on the machine and time whilst on the machine causing boredom (Moran et al 2009b).

This leads to another dominant theme of all the studies regarding the ways in which the experience of dialysis disrupts normality. Adaptive behaviours will be discussed in detail throughout the present review in order to demonstrate the complexities of treatment and how individuals cope, at the same time attempting to retain a sense of normality.

2.4.3 Normality and lifestyle

The focus of most studies reviewed has been an investigation of the experiences of patients on dialysis, and a major aspect of those experiences relates to the way dialysis affects and disrupts normal life. This encompasses a range of social, psychological, emotional and physical effects. Some studies adopt the negative view of a struggle for normality (Lindqvist et al 2000, Hagren et al 2001, Kiersans and Maynooth 2001, Dekkers et al 2005, Molzahn et al 2008), and others one of optimism and success in achieving some degree of normality (Rittman et al 1993, Curtin et al 2002, Martin-Mcdonald 2003, Curtin et al 2004, Velez and Ramasco 2006). Some describe this as losing normality and control, or to life being put on hold (Lindqvist et al 2000, Kiersans

In order to maintain a degree of control some individuals have undertaken an adaptive behaviour that involves fitting the treatment into their life, even modifying the therapy to achieve this (Keeping et al 2001, Curtin et al 2002, Polaschek 2003b, Curtin et al 2004, Ravenscroft 2005, Polaschek 2007). Some studies have identified that, although it may take immense effort, participants often endeavour to achieve some normality or to adapt to the “new normal” situation (Curtin et al 2002, Martin-Mcdonald 2003). This could be through employment, hobbies or socialisation (Walton 2002), but it also depends on how well they have adapted to the regime imposed upon them by the therapy. Reference is frequently made to diet and fluid control (Kierans and Maynooth 2001, Faber et al 2003, Polaschek 2003b, Ravenscroft 2005, Kaba et al 2007).

Some studies specifically describe the “self” as a feature of adaptation. Gregory (1998) describes the move from the old self to a new self, or as Rittman (1993) refers to it, “taking on a new meaning of being”. In two papers, Curtin et al. analyse this adaptation of self in some detail. Their studies examine the experiences of long-term survivors, those on dialysis for at least four years. The restructuring and transformation process is certainly not passive (Curtin et al 2002, Curtin et al 2004). Words such as “enduring” are often used when describing what it takes to remain positive (Gregory et al 1998, Dekkers et al 2005). Those patients regarded as successful in achieving this seem to have certain common attributes, and adopt positive expressions such as optimism, stoicism, autonomy, motivation, fighting spirit and self-assurance (Caress et al 2001, Hagren et al 2001, Curtin et al 2002, King et al 2002, Curtin et al 2004, Dekkers et al 2005, Hagren et al 2005, Polaschek 2007). In some cases these attributes may be linked to spirituality (Walton 2002, Tanyi and Werner 2008).

In a study by King et al. (2002), stoicism and good adaptation are linked to the patient’s moral standpoint, but the author’s do present some potential of bias, such as
the patient sample being from the North of England and the interviewer being a medical student, so the participants may have been keen to appear to be coping well (King et al 2002). Arguably, similar factors may also have influenced other interviews, and there are references within these studies of participants “putting on a front” and withholding information from the interviewer (Caress et al 2001, Keeping et al 2001, Polaschek 2007). This serves to emphasise the importance of the manner in which qualitative work is undertaken and the need for the researcher to be aware of the danger of inadvertently influencing the process.

Studies specifically related to home treatment emphasise the flexibility these treatments offer in comparison to in-centre dialysis (Lindqvist et al 2000, Keeping et al 2001, Curtin et al 2004). In Curtin’s (2004) study two main domains are described, autonomy and normality. The author describes the reasons patients give for choosing PD and the fact that they are very engaged in self-management, but there was considerable variation between individuals. Curtin (2004) also discusses how self-care can be affected by the beliefs of patients, and by the degree of control they maintain and their sense of empowerment. In his study of HHD patients Polaschek (2003) describes the effect of taking responsibility for their dialysis, but still feeling dependent on it as their life-line (Polaschek 2003b). Long-term survivors on HD describe self-worth and feelings of value as important factors in their fight to retain control of their lives. This has been confirmed in studies of PD patients by Keeping and English (2001) and Lindqvist (2000), in which gaining greater knowledge, and making the treatment work for them, has contributed to the process of managing patients’ own lives.

So far the techniques used by participants to regain control and to maintain normality through coping mechanisms have been described. Hope is also described, not only as a coping mechanism but also as a belief (Kaba et al 2007). How participants describe hope varies between hoping for a transplant, hoping for a cure and hoping for normality.

Hope may be related to living for the moment, belief in surviving, fulfilling one’s dreams and not dwelling too much on the future (Rittman et al 1993, Gregory et al 1998, Lindqvist et al 2000, Keeping et al 2001, Dekkers et al 2005). Some participants have used it as a means of creating positive thinking and optimism (Gregory et al 1998,
Hagren et al 2001, Walton 2002). It can be a struggle to overcome hopelessness and despair, and hope is one way of coping with uncertainty and becomes an integral feature of life, at the same time not to allow false hope to develop (Keeping et al 2001, Walton 2002, Martin-Mcdonald 2003, Polaschek 2003b, Moran et al 2010). The involvement of other patients, and sources such as faith and spirituality, are also helpful to some participants (Lindqvist et al 2000, Walton 2002, Tanyi and Werner 2008). These will be discussed in more details under the theme of spirituality. Hoping for a transplant is one way some participants deal with the times of despair (Martin-Mcdonald 2003, Moran et al 2010). Moran (2003) does put forward a view of enduring as a concept to describe individuals whose ‘life is on hold’ waiting for a transplant creating profound boredom and distressing moods (Moran et al 2010). At this point hope is taken over by these negative emotions.

Interestingly, patients who develop EPS will normally have been subject to self-care therapy over a number of years. Once they have been diagnosed with EPS, of course, this no longer applies, at least initially. How patients then adapt to the changes involved in yet another transition is an important consideration not yet fully investigated.

2.4.4 Meaning of illness

The meaning of illness was described by some authors explicitly and relates to how an individual takes ‘meaning’ from their experience. It is very much related to adjustments and strategies used by individuals as they learn to live with their long term condition. The concept of meaning of illness has become recognised and described from different perspectives; from the psychology discipline (Leventhal et al 1998) and from theories developed on coping and stress (Lazarus and Folkman 1984). Arguably all health models of health crisis have a common element, that patients representations are influenced by pre-existing belief structures (Sharpe and Curran 2006). How meaning is represented in the studies reviewed varied and only one study used a quantitative approach (Caress et al 2001).
The aim of the Caress et al (2001) study was to explore meaning using a schema based on (Lipowski 1983) and devised by (Degner et al 2003), in which patients were asked to select one option from eight choices offered. Additional open-ended questions added further understanding of the choices made. “Challenge” was the most common choice, selected by almost two-thirds (62.5%) of participants. The rationale for this was divided into positive and negative, as in “fighting spirit” and “fatalistic”, respectively. Participants viewed life as being full of problems and their striving for recovery. In this study prognostic information is mainly of concern to the transplant and pre-dialysis groups (Caress et al 2001). There are some interesting observations in the study relating to medical authority; the authors comment that patients who are determined to do well on treatment tend to take control and become self-managing, but not however to question medical authority, as seen in the other studies reviewed (Caress et al 2001, Faber et al 2003, Giles 2005, Polaschek 2007).

Gregory (1998) and Velez and Ramsco (2006) also discuss the specifics of the meaning of illness. Meaning from their perspective is shaped by past experiences and knowledge and involves a cognitive appraisal of the patient’s illness, life-style changes and critical events (Gregory et al 1998). This is expressed as “knowing versus doing”, and it includes knowing how to control negative feelings, knowing the diagnosis and decline of the illness and knowing the limitation caused by the regime. Doing, on the other hand, is the adaptation of behaviour to encompass this knowledge. This has been referred to in other studies in terms of personal attributes which lead to motivation and positive attitudes (Dekkers et al 2005, Polaschek 2007).

These results provide interesting observations regarding the meaning of illness, and although the word “meaning” is not always explicitly used by the authors of the qualitative studies, the meaning of illness is an element in many of the themes derived. This is supported by the work of other authors who have tried to define the meaning of illness (Fife 2005). Quantitative measurement of meaning does provide an objective assessment of the meaning individuals construct, as seen in the study by Caress et al. (2001). However, the subjective approach inherent in qualitative studies does provide a more personal and sensitive understanding, and cannot be dismissed in the search for meaning. Conversely, Thorne (1999) describes the levels of complexity ascribed to meaning and views qualitative work as a promising strategy in the pursuit of meaning.
Thorne (1999) also points out that the meaning individuals apply to long term condition is influenced by social and political contexts within the healthcare system and in society (Thorne 1999). This is particularly relevant in the studies included in this review of CKD due to the technology involved; the role patients play in the management of their disease, the healthcare environment and the effect on their social world (Kutner 1987, Gerhardt 1990, Faber et al 2003).

2.4.5 Emotions

The feelings and emotions expressed through these studies are often related to different stages of the journey. At the beginning, when patients are first diagnosed, expressions of anger, depression, anxiety, incomprehension, vulnerability and fear are common (Kutner 1987, Lindqvist et al 2000, Hagren et al 2001, Walton 2002, Hagren et al 2005, Kaba et al 2007). Some of these feelings may re-emerge at crisis points during acute episodes or admissions to hospital.

Throughout these studies a strong sense of emotion can be detected. For some patients the major factor was not being able to move beyond despair, and it is reassuring that most studies capture the fact that individuals adapt differently to similar circumstances. Kunter (1987) discusses suicide, pointing out that the suicide rate among dialysis patients is unknown. Little else was expressed on how this is measured, an assumption being that individuals on haemodialysis may in fact influence their ability to commit suicide by forgoing treatment and consciously not adhering to diet and fluid control. Emotions described in these studies may seem an abstract factor but when studying experiences the patient’s voice will undoubtedly be loudest when describing the emotions they have experienced.

2.4.6 Physical effects

The physical effects of renal failure and dialysis in these studies focus on how they affect individuals on a day to day basis. Rather than an objective measurement of the symptoms, patients refer to them in terms of suffering or enduring. The side-effects of both HD and PD are regarded as negative effects (Lindqvist et al 2000, Keeping et al 2001, Curtin et al 2002, Curtin et al 2005). The physical effects are often related to a
reduction in physical activity (Kaba et al. 2007). Symptoms such as pain, fatigue and itchiness are described, but participants often comment that these are not regarded as important by healthcare providers. Faber (2003) and Polaschek (2007) relate this to the dominant medical doctrine that patients are deemed to be “well” as long as their biomedical and clinical indicators are normal. For example, a patient may have restless legs or itchiness, which impose considerable problems in everyday life, but these are often ignored as minor symptoms. Curtin (2004) also points out that physical symptoms can impact on the way in which a patient manages his own treatment.

2.4.7 Relationships: Families and healthcare professionals

Studies of experiences on dialysis frequently make reference to families, relationships and healthcare providers, as these all form an integral part of the support structure. Firstly, families are referred to in a mainly positive sense as an important source of support, both emotionally and financially. On the other hand the impact on the family may also be profound as patients become progressively more dependent on them (Kutner 1987, Gregory et al. 1998, Hagren et al. 2001, Keeping et al. 2001, Polaschek 2003b, Dekkers et al. 2005, Hagren et al. 2005).

Some studies have highlighted the fact that family relationships can sometimes be strengthened as a result of the illness (Polaschek 2003b, Molzahn et al. 2008) and this may provide motivation (Polaschek 2003b, Dekkers et al. 2005).

The financial and broader social effects have been studied in detail by Gerhardt (1990) and Kutner (1987), both studies concentrating specifically on the social effects of living with dialysis. Kutner in particular describes the social worlds of these patients, focusing on family, relationships and roles. Gerhardt (1990) maps out the illness trajectory of a group of men on dialysis aged between 20 and 50 and their spouses in terms of an “illness career”, using a sample designed to capture the socio-economic and work-related changes resulting from CKD. This sociological enquiry uses multiple biographical narratives extending over a period of 12 years. The study describes the effect of dialysis on marriages and families in terms of traditional working roles and patterns, and how families respond to the need to maintain financial stability. The
theoretical basis for this study arises from medical sociology, in which it tends to be assumed that the chronically sick cannot contribute to the labour market and that long term condition “constitutes deviance” and is characterised by “discrimination and stigmatisation”. However, the study concludes that this is not the case and that illness careers can be accommodated within normal life and society (Gerhardt 1990).

The role of healthcare providers is also described in the studies, again with both a positive and a negative influence. Patients undergoing in-centre dialysis refer to the impact of staff within these units. Participants are conscious that they are dependent on the staff, indeed that their lives are in their hands (Kutner 1987), and that they are therefore beholden to them (Faber et al 2003). The level of support required is related to the expertise of the staff, the degree of trust in them and of wanting to share in the decision making (Gregory et al 1998, Walton 2002, Curtin et al 2004, Ravenscroft 2005, Kaba et al 2007). These positive aspects depend on a caring attitude and appreciation on the part of both medical and nursing staff. Nursing staff play a more dominant caring role than medical staff, the latter being mentioned as not being present often enough. However, some participants experience loneliness and social isolation (Kaba et al 2007, Molzahn et al 2008), resulting in “putting on appearances”, and not disclosing complete information to healthcare professionals (Lindqvist et al 2000, Caress et al 2001, Hagren et al 2001, Polaschek 2003b). Some patients choose to become part of the dialysis community, whereas others prefer to separate themselves from it (Kutner 1987, Walton 2002, Faber et al 2003)

The dominant attitude of medical and nursing staff is expressed negatively by patients in some of the studies. Giles (2005) has characterised this as a medical discourse which overpowers bodily sensations and feelings. The asymmetry of the relationship and the medicalisation of symptoms are frequently mentioned (Keeping et al 2001, Kierans and Maynooth 2001, Faber et al 2003, Velez and Ramasco 2006, Polaschek 2007). The paternalistic approach to how HCP’s deal with patient problems seems to create negative feelings with some patients on dialysis. In studies of self-care patients, learning the medical language is seen to be an important feature of the process (Keeping et al 2001, Curtin et al 2004, Polaschek 2007). Faber (2003) discusses the biomedical community and how patients within this arena learn to speak using a limited medical discourse.
Some of the studies described how patients struggle with the concept of appearing well to others who view them, but feeling ill (Kutner 1987, Keeping et al 2001, Kierans and Maynooth 2001, Polaschek 2003a, Tong et al 2009). This view is perhaps why they often feel the medical and nursing interactions don’t pay enough attention to their complaints of how they feel physically.

2.4.8 Body image

Dialysis can have a profound effect on body image, characterised by the presence of the fistula in a patient on HD and the catheter for those on PD (Muringai et al 2008). Studies make reference to the stigma attached and the disgust sometimes felt as patients become increasingly aware of their bodies (Lindqvist et al 2000, Kierans and Maynooth 2001, Curtin et al 2004). There may also be a more existential concept of the body, as it is sometimes reported that due to dependency on the machine a patient no longer owns his body (Giles 2005). Giles uses Van Manen’s (1997) work encompassing the concept of the lived body and the subjective experiences participants had with their dialysis machine. This concept relates specifically to the body as a physical entity in the world of dialysis and is also strongly linked to Merleau-Ponty’s work on the phenomenological perception of the body (Giles 2005). In a study of HHD Giles (2005) discusses the patient’s relationship to the machine. Although adopting a slightly different perspective from Rittman et al. (1993) on patients on HHD, the lived space again comes across, particularly their experiences in the hospital setting, problems due to isolation, and intrusions caused by the transformation of the home into a hospital-like environment. In terms of lived relations these participants also describe the struggle between the body and machine. The lived body relates to the medical discourse and practice that transforms “the bodily experience of the participants” (Giles 2003). Similarly to Faber (2003), Giles makes reference to the power of the medical–functional discourse, in particular over bodily feelings and sensations. Since HD affects so many features of the body, particularly in terms of the access (fistula and lines) and the machine itself, this is quite a powerful experience (Giles 2003).

Kierans and Maynooth (2001) also refer to the concept of the body in their phenomenological study, in relation to the changes of bodily sensation through the
process of diagnosis and dialysis, in particular the effects of the fistula in HD and the physical sensations and pains experienced. In Curtin’s (2004) study of long-term PD, these patients come to terms with the body image problem and move forward, not allowing it to interfere in their lives.

2.4.9 Suffering

Suffering is a word used in many studies to describe the physical and emotional turmoil of the participants (Rittman et al 1993, Faber et al 2003, Polaschek 2003b, Dekkers et al 2005). A study by Hagren (2001) uses suffering as a focus to explain the losses felt as a result of HD, discussing such aspects as loss of freedom, and stress and strain on the family. Hagren (2001) describes the concept as taking place at three levels, firstly suffering as related to sickness and treatment, at the second level related to the care provided, and at the third level suffering related to each person’s unique life and existence (Hagren et al 2001). The authors describe the ultimate suffering as the fear of death, which is always present. Hagren (2001) describes existential optimism being used to alleviate suffering. Reflections on the illness, hope and expectations, combined with fear of what may happen if the machine fails to work, all add to the suffering. One of the limitations of both Hagren’s studies is the nature of the interviews. These were very brief, due to the frailty of the participants. This may have limited the depth and richness of the responses, an essential component of qualitative investigations (Popay et al 1998). Kiernan and Maynooth (2001) point out that constructions and reconstructions of suffering are seldom incorporated into the biomedical model. Alleviating suffering is encompassed in many ways, as have already been discussed; endurance and perseverance are words used by participants to express their way of coping with suffering. In contrast to the other studies, Hagren (2001) also includes waiting for a transplant as an example of suffering.

2.4.10 Spirituality

Two studies have used spirituality as the focus of experiences and these provide a slightly different perspective (Walton 2002, Tanyi and Werner 2008). They describe how spirituality can be used by participants as a solid coping mechanism. The findings relate well to the way this group of patients have used spirituality to gain acceptance of their illness and to help them to come to terms with the possibility of death (Tanyi
and Werner 2008). However they only included women in the study. Other themes described by these authors include fortification, which is the inner strength that gives individuals the will to live and also to help others. Understanding this involves learning about the illness and self-care. A further theme is emotional modulation, or fostered coping, which helps to reduce anger, reduce depression, provide support and promote happiness (Tanyi and Werner 2008).

Walton’s (2002) study is similar and describes as a central element the search for a balance in life between mind, body and spirit. The phases used by Walton (2002) are similar to those of Tanyi and Werner (2008) and are related to accepting and confronting mortality and reframing one’s life by adopting a positive outlook, a technique used for restructuring and reorganising one’s thoughts and beliefs. Other themes described relate to how patients adjust to their illness by means of spirituality and are able to face the challenges. These are not linear processes but can be used at different times and in times of crisis. Walton (2002) also describes faith as a guide to decision making, providing a moral and ethical basis which participants can apply throughout the process. The spiritual “presence” gives inner joy and strength and allows participants not only to seek help themselves but also to want to give it back (Walton 2002). The essence of giving back arising in these two studies is unique and has not been detected in any other studies. Both emphasise that spirituality is not merely religious belief but can be something arising from some “higher” level or from within the individual’s own belief system.

Other studies have occasionally made reference to spirituality, but often in a negative sense when participants have searched for meaning, blaming their illness on spiritual factors or on divine intervention (Caress et al 2001, Dekkers et al 2005, Velez and Ramasco 2006). This could be explained by the way these studies were conducted and the questions used. Interestingly, many of the coping behaviours arising through spirituality are found in the other studies and can therefore be regarded as illustrations of an inherent human quality.

Although not connected with spirituality as such, Dekkers et al. (2005) use the ethical Aristotelian principle of virtue to study how dialysis patients’ stories have embodied specific moral principles. Again the focus on coping seems inherent, but the question is
related to the ethics of virtue – for instance: “How should I live a good life?” – and the specific moral qualities needed to achieve this. The theory is based on the assumption that a long term condition is associated with misfortune, so how is such a person going to live a good life? Many aspects of these results have been included in the narrative so far, as they relate to experiences, challenges, attitudes and moral qualities. Although the term “virtue” was not explicitly used in the questions or in the narratives, the authors refer to them using terms such as “perseverance”, and knowing and keeping a balance, a sense of reality, activity, gratitude, and having a good relationship with others, all of which seem to feature in a good life on dialysis (Dekkers et al 2005). The elements pointed out by the author may well be encountered in persons without long term condition, as is the case with many other attributes that have been discussed in the course of this review. They therefore equip patients to cope and adapt to the whole range of challenges they face.

2.4.11 Summary

The purpose of this review was to identify research on “the lived experience of dialysis” and the meaning of the experience. The studies, with one exception, were all qualitative, indicating the philosophical underpinnings of such research questions.

The themes and concepts described from the findings of these studies can help to provide understanding of the multidimensional and complex experiences of individuals living with CKD. While the majority of the studies focus on in-centre HD, there are common elements across all modes of RRT. There is however an over-representation of participants on HD compared to PD, in fact there is a clear lack of studies of PD patients alone. Unlike the other studies, the HD experience relates to the machine, time spent on the machine, the environment and the side-effects. It is difficult to determine whether the medical discourse was more predominant in the HD patients than those on PD. There were also studies that only included either men or women, often from white backgrounds. It could be said that different ethnic minorities and gender are not truly represented in these studies. On the basis of this, cultural differences are rarely referred to, in fact only one study used culture as its focus (Kaba et al 2007).
The studies included in this review provide useful insights into the sociological considerations and psychosocial issues for individuals living with CKD. The coping and adaptation perceived in these studies relate to their journey from diagnosis up to starting dialysis and their continued lifetime on dialysis. From the studies in this review the meaning of illness, unless explicitly described, was often viewed differently; some studies concentrate on the negative aspects of CKD and others the value and positive features of the adaptive process. These conflicting views can be assigned to the different theoretical and methodological approaches, and experience of long term condition was also a common element in a meta-study carried out by Thorne (Thorne et al 2002).

There are however some important points in this review that deserve further study. It is clear that attributes such as optimism, stoicism, positive behaviour and spirituality provide individuals with the ability not only to endure illness but also to move to a reformed self. Part of that process is a sense of control, which was more evident in studies of self-care treatments. What the studies do not reveal is the relationship between these attributes and outcomes, but it is clear that an ability to manage self-care treatments allows individuals to resume many of their normal activities. It is clear that hope is valuable, but uncertain whether hope on its own can provide individuals with the attributes mentioned or whether the two go together. Individuals use expressions such as “striving for normality”, and this is where the meaning of the illness can be seen. Certain studies that relate to how EPS may be experienced are similar to those of PD patients and long-term survivors. However, only two studies examined PD patients alone (Keeping et al 2001, Curtin et al 2004). These studies demonstrate a positive outlook, with participants adapting and managing self-care dialysis while retaining a sense of normality. Although there were occasional references to setbacks and in one case an acute episode (Curtin et al 2004), EPS is not mentioned. EPS is a major issue, and its implications deserve further investigation.

The literature review provides a focus and context for the current study. There is a clear need to expand the current knowledge base of EPS. A greater understanding of the implications of EPS is required, including how information should be
communicated to patients and how the risks can be managed in the PD population. A good starting point is by examining EPS from the patient perspective. The aims of the present study are described below.
2.5 Study aims

The primary aims of the present study were:

- To explore patients’ understanding of EPS in the context of their “life” journey on dialysis.
- To examine the meaning and impact of the condition, as constructed by individual patients.

The Objectives therefore are:-

- To explore patients understanding of EPS, including their condition-related knowledge and information needs.
- To explore the symptoms of EPS as perceived by patients and how these are considered to have impacted on their lives.
- To explore patients’ views of PD as a therapy.
- To explore the perceived impact of the surgery for EPS as an ‘embodied experience’.
- To explore support structures and mechanisms used by individuals following the diagnosis of EPS.
Chapter 3: Methodology

The research design must obviously aim to answer the research questions, but it is also influenced by the nature of the study. In the present study an overview of the research paradigm indicates a strong case for the employment of qualitative research based on hermeneutics.

The chapter begins by considering the paradigm chosen and the epistemology of the study, followed by the methodological approach. This provides an introduction to Chapter 4, in which the applied methods are discussed.

3.1 The research paradigm

The research paradigm for a study has been described as:

*Patterns or beliefs and practices that regulate enquiry by providing lenses, frames and processes through which investigation is accomplished* (Weaver and Olson 2006).

The research paradigm provides a guide for a disciplined enquiry and is characterised by epistemological, ontological and methodological issues, and also by the theoretical perspective underlying the methodology (Guba 1990, Crotty 1998).

According to Pope and May (1995) epistemology is the theory of knowledge, and the scientific study of knowledge which deals with the nature and validity of knowledge. Ontology is described as being concerned with “what is”, and therefore explores the nature of reality or existence (Pope and Mays 1995, Crotty 1998). The methodological approaches are guided by the specific theoretical framework and relate specifically to the underpinning paradigm.

3.1.1 Constructivism and Interpretivism

According to Crotty (1998 pg 8) epistemology falls into three categories, objectivism, subjectivism and constructionism. Objectivism assumes that an observer remains
detached, and that meaning can be said to exist independently of our thoughts and consciousness (Crotty 1998). The ontological basis of objectivism is that of objective realism, which is that reality is governed by immutable natural laws (Guba 1990). These epistemological and ontological beliefs are often, but not exclusively, aligned with quantitative approaches to research. The methodology is concerned with hypotheses that can be tested in a deductive scientific manner, such as those employed in the natural sciences. The objective is to use procedures that can be carefully regulated and to eliminate any interaction on the part of the researcher within the process.

Other epistemological perspectives described by Crotty (1998) are subjectivism and constructionism; these are more closely linked to the qualitative paradigm. Subjectivism implies that meaning is imposed on the object by the subject and excludes any interplay between the two, in other words between the researcher and the participant (Crotty 1998). Constructionism, on the other hand, takes the view that there can be no meaning without the mind, and that meaning is constructed by human beings as they interact with the world they are describing (Crotty 1998). Constructivism is another term used by Crotty (1998) but is not given as a separate epistemological perspective. It is based on the unique experience of an individual person and focuses exclusively on “the meaning making activity of the individual mind” (Crotty 1998). It suggests that any person’s method of making sense of the world is just as valid and worthy of respect as any other. On the other hand, social constructionism emphasises the influence one’s culture has on each of us and its effect on the way we view the world (Crotty 1998). Constructivism is thus the opposite of objectivism, and adopts the view that that there is no such thing as objective truth waiting to be discovered, indeed that meaning is not discovered but constructed (Crotty 1998). Different people may therefore find different meanings in any given situation.

Constructivism is often used interchangeably with the term interpretivism, and different meanings of these terms are encountered in the literature (Guba 1990, Crotty 1998, Racher and Robinson 2003). The confusion this causes has been discussed in detail by Guba and Lincoln (1990), and other authors who use these terms interchangeably have invented the combined word, constructivism-interpretivism (Walker and Dewar 2000, Appleton and King 2002, Ponterotto 2005). Guba and Lincoln
(1990) take the view that epistemologically the constructivist takes a subjectivist approach to examine the phenomenon being studied, but to Crotty (1998) subjectivism (described above) has a different meaning. Crotty (1998) asserts that interpretivism underpins constructivism as a theoretical perspective that guides the researcher in his approach “looking for culturally, derived and historically situated interpretations of the social life world” (Crotty 1998, Appleton and King 2002). In both cases, however, interpretivism is aligned to a methodological approach of hermeneutics, although it is not a specific method. Hermeneutics refers to interpretation of text, or “letting the text speak for itself” (Hans 1978), and is an ancient discipline originally used for interpreting biblical texts. Its use as part of the philosophical and methodological procedures in qualitative research will be discussed in greater depth later in this chapter.

Interpretivism also describes the investigator and the object of investigation as having an interactive linkage, and that multiple ways of knowing are required to achieve knowledge (Racher and Robinson 2003). The goal therefore is to understand the lived experience from those who live it (Ponterotto 2005). The basis is that throughout the research process the researcher must interact with the participants being studied, to gain access to the multiple views of reality that are present (Appleton and King 2002).

Objectivism (Crotty 1998) has been rejected as an epistemological perspective on the basis of detachment from the research process. The current research sought to explore the experiences and meaning of EPS from the perspective of the patients. It was not therefore possible to undertake the study in a wholly objective manner. In terms of where I have positioned myself as researcher and clinician, I have accepted that my role within the research process could not be objective. As a researcher I would be engaged in the study in an interactive way, bringing to the process my own views of reality and my past experience, prejudices and biases. The participants also brought to the process their experiences of living with a long-term condition. The multiple views of reality would therefore potentially be complex and interrelated.

The view of multiple realities that are socially constructed also relates to the ontological view of interpretivism (Koch 1999, Ponterotto 2005). It accepts that we are all self-aware and as such are self-interpreting. Koch (1999) points out that, within the
research process “together with participants you would create constructions and perhaps you would reach consensus about the construction that makes the most sense” (Koch 1999). The epistemological perspective of the constructivist-interpretivist is one of the foundations of qualitative research methods (Ponterotto 2005).

3.1.2 The qualitative paradigm

Within the qualitative paradigm and the above perspectives there are a number of possible methodological approaches. Each of these will be considered so that the approach chosen for the present study can be described. However, it is important to bear in mind that in following the constructivist-interpretivist approach the researcher becomes part of the participant’s life world. The methods employed therefore need to allow this to take place by using observational study or face to face interviews. These procedures are described in more detail later.

Firstly, a selection of the different qualitative methods or methodological approaches are described, and are summarised in Table 2 below.
### Table 2 Qualitative Methods and Approaches

<table>
<thead>
<tr>
<th>Methodology</th>
<th>Epistemological position</th>
<th>Theoretical perspective</th>
<th>Analytical procedure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grounded theory</td>
<td>Constructionism/interpretivism</td>
<td>Symbolic interactionism. Constructing theory from data</td>
<td>Coding/ categorising Continues until data saturation achieved</td>
</tr>
<tr>
<td>Ethnography</td>
<td>Constructionism/interpretivism</td>
<td>Anthropology Study of human behaviour in particular culture</td>
<td>Field notes/ codes categories to generate meaning. May incorporate a range of methods, both quantitative and qualitative</td>
</tr>
<tr>
<td>Phenomenology</td>
<td>Interpretivism</td>
<td>Husserl’s philosophy</td>
<td>Bracketing used to describe the essential meaning of phenomena</td>
</tr>
<tr>
<td>Hermeneutic phenomenology</td>
<td>Interpretivism</td>
<td>Philosophy derived from phenomenology, but uses hermeneutics as an approach to interpretation</td>
<td>Thematic analysis. Case study exemplars and shared understandings.</td>
</tr>
</tbody>
</table>


Having examined the methodological approaches, phenomenology was studied in greater depth, as it was considered most appropriate to the research aims and appealed to my own instincts as a researcher. Ethnography was rejected, on the basis that much of the data being generated would be based on beliefs and perceptions, involving interaction with the interviewer, and therefore would not be observable, as
would be expected in an ethnographic study. Ethnography is concerned with the way the behaviour of individuals is influenced by the culture in which they live and is focused on this process (Parahoo 2006). Grounded theory was also rejected, as it is underpinned by symbolic interactionism and is more relevant for studying changing patterns of social systems (Rizzo-Parse 2001). It is an inductive approach for generating new theory from the data (Patton 2002). Although initially grounded theory seemed of interest, it was only after close examination of the philosophy of phenomenology and in particular hermeneutics that it was realised which approach would be best for answering the research question and aims.

Although other approaches have been used, phenomenology has been extensively employed in nursing research to uncover meanings and experiences. Within phenomenology differences in the underpinning epistemological stance and the theoretical perspectives became apparent. As a philosophy, phenomenology may be defined as the study of experiences or consciousness (Moran, 2000). The term phenomenology has in fact been used to describe a research method, a philosophy and an approach (Dowling 2003).

### 3.2 Phenomenology in nursing research

Before describing the processes and applications required for this study it is helpful to consider how phenomenology has been applied to nursing research in the past. There have been many criticisms and much debate about its philosophical position, including lack of clarity and description, not only in the methods but also to the process of analysis and the researcher’s own position within a research study. However, the fundamental reason that nurses have used the phenomenological philosophical stance has been its clear relevance within nursing practice (Van Der Zalm 2000).

Some nurses have used phenomenology to study the essential features of nursing practice, including caring (Milne and Mcwilliam 1996), comfort (Morse et al 1994) and empathy (Baille 1996). These researchers have mainly considered nurses as the participant group in order to define the concepts involved in everyday nursing practice. Lindseth and Norberg (2004) point out that part of the research process lies in
reflection, in other words that reflecting on our experience of healthcare will help us to identify ways of improving practice (Lindseth and Norberg 2004). Van der Zalm discusses the work of a number of researchers in an attempt to define theory relevant to nursing, and how phenomenology can provide nursing with a descriptive and explanatory theory without becoming predictive or prescriptive (Van Der Zalm 2000).

Benner’s comprehensive study of nursing practice from novice to expert has used hermeneutics, and this work has stood the test of time, generating both books and theory (Benner 1984). Her study has been used to enhance the way nurses can work and develop, to help understand everyday practices and meanings, and to value the knowledge underlying skills, stress and coping mechanisms (Benner 1985).

More pertinent to the present study are examples of phenomenology used in patient groups to understand “lived” experiences. There are many examples of this in the literature, and those quoted are only a selection (Rittman et al 1993, Koch 1996, Bergman 2001, Lillibridge 2002, Lindseth and Norberg 2004, Stephen 2004, Lindahl et al 2006, Lindahl et al 2007, George and Thomas 2010). Although these studies adopt slightly differing approaches, their common objective is to understand the experience of living with a particular illness. Although they provide some insight, their assessment is not entirely relevant to the positioning of the current study. In particular, where and how the researcher is placed within the study and the use of reflection are both poorly represented. There are of course limitations imposed by publishers on word count, but this is a common weakness. Descriptions of analytical procedures are in general good, most importantly in the way the analysis was undertaken. A further discussion of analytical procedures will be reviewed in the data analysis section.

While these features are important and need to be made clear in interpretive studies, they emphasise the need for nurse researchers to adopt a detailed research design and to be aware of the implications of what has been described as the methodological foundations (Thorne 1997).

Nurses bring to their research their experiences of the way they live and practise within their own individual world. The demands of their practice and their clinical knowledge naturally influence the topics they wish to investigate. Nurses are therefore
searching for methodologies in which life and times of the patient can be given a voice (Lawler 1998):

*Nursing has turned to phenomenological philosophy because the nature of the subject matter to be investigated invites a human approach that does not reduce the person to a set of physiological or pathological descriptions or probability statements; and if phenomenologies have been found to be wanting as methodologies in nursing research it is maybe a reflection of the complexity of nursing as much as a comment on the way in which nursing practices are culture sensitive.*

An overview of the philosophy of phenomenology is essential to provide the theoretical background to the study.

**3.3 The origins of phenomenology**

Phenomenology has its origins in philosophy, resulting from the earlier work of René Descartes (1596–1650), whose name has given rise to the term Cartesianism (Honderich 1995). Descartes was interested in the distinction between a person’s mental and physical being, described as dualism, which led to his attempt to link all knowledge to the realm of science (Byrne 2001). The Cartesian belief is often referred to by philosophers of phenomenology who oppose it in favour of a different approach to the understanding of knowledge and human experiences. However, within phenomenology there are differing approaches as to how this may be achieved.

It is important to outline the different philosophies associated with phenomenology, since much of their criticism within nursing literature is due to the lack of clarity they are given (Crotty 1997, Lopez and Willis 2004). This is mainly a feature of nursing literature that adopts phenomenology as its chosen method but does not follow any specific philosophy, and this “can result in research that is ambiguous in its purpose, structure and findings” (Lopez and Willis 2004). The differences between the elements of the philosophy explain and justify the methodological approach chosen for the present study. Phenomenology has been described as a philosophical “movement”, on the basis that it is dynamic and evolutionary (Laverty 2003, Lopez and Willis 2004).
The principal figures in phenomenology are summarised below (table 4), and their perspectives are discussed in the section following.
<table>
<thead>
<tr>
<th>Principal Philosophers</th>
<th>Perspectives</th>
<th>Application</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Husserl (1859–1938)</strong></td>
<td>Developed a philosophy of human experiences pre-reflectively without interpretation.</td>
<td>Descriptions of experiences using bracketing and reduction to describe the phenomenon experienced</td>
</tr>
<tr>
<td>A German philosopher- Ideas</td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>General Introduction to Pure Phenomenology</em> (1913)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Heidegger (1889–1976)</strong></td>
<td>Focused on ontological aspects and understanding</td>
<td>Interpretive process by using hermeneutics.</td>
</tr>
<tr>
<td>German philosopher – <em>Being in Time</em> (1927)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Merleau-Ponty (1908–1961)</strong></td>
<td>Emphasised the role of the body in human experience</td>
<td>Interpretive process</td>
</tr>
<tr>
<td>French philosopher <em>Phenomenology of perception</em> (1945)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Gadamer (1900–2002)</strong></td>
<td>Used the Heidegger philosophy but went further in his development of hermeneutics.</td>
<td>The fusion of horizons and the prejudices of the researcher are part of the process of interpretation</td>
</tr>
<tr>
<td>German philosopher – <em>Truth and Method</em> (1960)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Paul Ricoeur (1913-2005)</strong></td>
<td>Continued Gadamer’s hermeneutics but incorporated distanciation and critical hermeneutics</td>
<td>Interpretive approach- more critical in dealing with pre understandings</td>
</tr>
</tbody>
</table>
3.3.1 Edmund Husserl (1859–1938)

Husserl was a German philosopher, credited with being the founder of phenomenology (Honderich 1995). The fundamental driving forces within Husserl’s philosophy were a departure from the more positivist approach to science and his belief that experience was the source of knowledge. He opposed what he described as naturalism – the “view that empirical science is the sovereign of truth” (Husserl 1913, Levasseur 2003). In accepting the phenomenological method as a new science which leads to true meaning, he departed from the Cartesian concept of the duality of reality, as something which exists completely separate from the individual (Koch 1995, Laverty 2003).

Husserl began his career as a mathematician but soon became influenced by the work of the psychologist Franz Brentano, and switched his emphasis to philosophy. Part of his early work was a criticism of the tendency to regard psychology as a science, which attempted to apply the methods of the natural sciences to human issues (Laverty 2003). According to Laverty, Husserl emphasised that humans did not merely react automatically to external stimuli but rather responded to their own perception of what these stimuli meant. Husserl adopted the term “life world”, which implies that our everyday experiences form the primordial nature of consciousness (Husserl 1913). The life world is an expression used in phenomenology and, although first described by Husserl, it is now widely used by other writers (Gadamer 1975, Van Manen 1997). Drew amplifies the concept further (Husserl 1913, Drew 2001):

Phenomenology makes clear that consciousness is a creative participant in the relationship between ourselves and the world that we call experience. Our residency in the life world places us in a position of creative contributors with that world. As researchers we must keep in mind that the things that we study are always seen through the collaborative lens of our perceptions.

This is an important point, since it acknowledges the role of the researcher in a phenomenological study, and this will frequently be referred to later when discussing the actual methodology and reflexivity within the study. An assumption specific to
Husserl’s philosophy is that experience as perceived by human consciousness has value, and may therefore be a relevant subject for scientific study (Lopez and Willis 2004).

Husserl’s view of consciousness is that it is an intentional process, actively guided by human will, so that the mind is directed towards the objects of study (Laverty 2003). Intentionality refers to the relationship between persons and the objects or events within their experience, or to the directed awareness of an object or event (Drew 2001). This implies that there is always an intentional relationship with those things that make up our everyday lives, within the life world described above (Drew 2001). The aim of phenomenology is thus to interpret an object or event as something meaningful. It is worth noting that the term “object” relates to things in the everyday world, including facts, concepts, pain, consciousness, dream images, essences – or virtually anything (Paley 1997).

Husserl’s intentional focus was to develop descriptions of particular realities or to come face to face with the ultimate structures of consciousness, which he referred to as “essences” (Laverty 2003). The essences are sometimes described as universal patterns of experiencing, or eidetic structures (Dowling 2003), and their meaning can be extended to represent the true nature of the phenomena being studied. From this point of view the essences can be abstracted from the lived experience and may represent reality without considering the historical context (Dowling 2003). In Husserl’s phenomenology this is the point at which objectivity enters the research process, and is described as “bracketing”.

Bracketing, or époché, is perhaps the most controversial and debated aspect of Husserl’s work. This is the aspect of phenomenology in which researchers endeavour to describe universal patterns or experiences as faithfully as possible. In order to achieve this Husserl refers to a factor described as transcendentality (Dowling 2003). This acknowledges the need for the researcher to be self-aware and to shed all prior knowledge, in order to fully grasp the essential lived experiences being studied (Dowling 2003, Lopez and Willis 2004). The process of transcendent subjectivity means that the researcher must constantly guard against preconceptions and bias which might influence the study (Lopez and Willis 2004). Husserl acknowledges that as researchers we are ourselves immersed in the life world and we therefore become
part of the process – arguably a feature of all qualitative studies. The term bracketing is applied, meaning that the researcher can “bracket off” any such preconceptions and bias that he brings to the process (Koch 1999). Bracketing implies suspending one’s natural assumptions, so that the essential features of consciousness can be understood, free from prejudice (Levasseur 2003). This process is sometimes described as “reduction and reflection”.

There are those who argue that Husserl was attempting to apply objective science to an impossible situation, partly because it returns to the Cartesian belief in separating consciousness and the thinking process from the world (Salsberry 1989, Koch 1999, Levasseur 2003). In the beginning when examining phenomenology I realised that the Husserl approach would not be fitting with the current study, on the basis that I would not be able to bracket my previous experience and assumptions. My experience not only of patients on peritoneal dialysis, but also my knowledge of EPS could not be put to one side in an objective way.

If the philosophy chosen is Husserl’s, the researcher has to demonstrate how bracketing is to be achieved and how the “essences” and universal structures will be described within the study. Research following the Husserl philosophy is said to be “descriptive”.

3.3.2 Martin Heidegger (1889–1976)

A German philosopher and a former student of Husserl, Heidegger is best known for *Being and Time*, written in 1927 (Inwood 1997). This work is acknowledged to be difficult to understand, particularly since its structure and language create problems in translation. Heidegger’s work may be said to have reintroduced the concept of hermeneutics. This is an ancient discipline associated with interpretivism and was applied in the seventeenth century to the interpretation of biblical texts (Crotty 1998). It has already been described briefly in the outline of the epistemological position of the present study. Unlike Husserl’s standpoint, hermeneutics emphasises the importance of language and has been created within a social and historical background (Allen 1994). It is based on the assumption that humans experience the world through
language, and that language provides both understanding and knowledge (Byrne 2001). The underlying question that concerned Heidegger was what it means “to be”. For Heidegger, the emphasis was on the ontological perspective; the nature of reality was more concerned with the study of being, or the question: “What does it mean to be a person?” (Koch 1999).

To Heidegger human beings were not substances, and he considered that we are what we do – only human beings really exist (Mackey 2005). He was concerned with the actuality of being human. The word he used was Dasein, which he defines as within us, and what it means to be human (Heidegger 1927:1962, Inwood 1997). While Heidegger clearly wrote in considerable depth about the issues of “being” and its position within the world, it was his philosophy underlying its understanding that led to hermeneutics. In his hermeneutic phenomenology, sources are not phenomena, and he tries instead to explain “being” in terms of the structure of human life itself (Koch 1999). This is different from Husserl’s view of intentionality, in which consciousness is an intentional process directed by the objects of study (Johnson 2000).

Hermeneutics is thus an interpretive process used to uncover meanings (Koch 1995), and this is why nursing scholars tend to draw on Heidegger’s work. Heidegger also departs from Husserl in the way bracketing can be used to suspend one’s prior knowledge and pre-understanding of a phenomenon. These do not sit comfortably with Heidegger’s interest in “being”, since existence is only recognised in relation to others, and to other objects (Heidegger 1927:1962). Interpretations then have both fore-structures (presuppositions) and an as-structure (meaning) (Johnson 2000). The issue of meaning then concerns how “being” relates to others and other objects, or as Heidegger says, “‘being in the world’” (Heidegger 1927:1962). According to Johnson (2000):

*Being-in is not a spatial relation but rather indicates the way that human beings relate to other entities in a familiar world of involvement* (Johnson 2000).

Heidegger (1927) describes this initially in terms of everyday objects or entities within the world, such as the tools that are employed. In his description of the world he does not imply a totality of such entities but rather an interconnected context of involvements that give meaning to everything one encounters (Johnson 2000).
In the second division of *Being and Time* Heidegger (1927) moves to temporality. For Johnson (2000) this adds depth to the understanding of his philosophy and makes it more relevant to nursing research, potentially providing the framework for investigating the meaning of individuals’ experience within the context of their lives (Johnson 2000). Temporality means that time cannot be separated into past, present and future, and he describes resolute *Dasein* as running ahead to its death, and for humans this means that death is the ultimate meaning-giving possibility (Inwood 1997, Johnson 2000, Mackey 2005). His description of authenticity refers to *Dasein* always reaching into the past before deciding on the present, and he explains that this perspective of time is not merely the continuing process of being human. How as humans we decide between the many possibilities of how to live is always a process of “becoming” (Johnson 2000).

In keeping with Heidegger’s work, the principle is to relate the ontological perspective and interpretation to gain an understanding of meaning within the text or language. Within that:

*Being-in-the-world as temporality reminds us that our lives are unified and connected within the whole of our significance.....In research the participant’s experiences and the meaning of these experiences cannot be separated from the whole of that person’s world* (Johnson 2000).

This is a central tenet of hermeneutics, namely that the participant’s individual experiences cannot be removed from the context of their whole life experience. On the basis of this it became clear to me that Heidegger’s’ philosophy would be part of the study as has already been mentioned the individuals included in the study would have experienced a life on dialysis. This would be their ‘life world’ and be part of how they describe their experience of EPS. Heidegger’s philosophy also encompasses a way of understanding through the experience described by individuals; this level of ontological understanding to gain meaning would help to uncover the “meaning” of EPS.
3.3.3 Hans-Georg Gadamer (1900–2002)

Gadamer, again from Germany, began as a student of Heidegger, and his most famous work, *Truth and Method (1960)*, was not published until he was 60 years old. He incorporated the work of both Husserl and Heidegger in his description of phenomenological understanding. In particular, in his interpretation of text and the study of language Gadamer was concerned with historicity, tradition and authority (Hans 1978). Although he wrote extensively about historical texts he also promoted the view that we are essentially historic beings, so how we relate to the past “is not characterised by distancing and freeing ourselves from tradition; rather we are always situated within traditions and this is no objectifying process” (Gadamer 1975 pg 283). These concepts help to explain how Gadamer relates to the hermeneutic interpretive process of texts and language to gain understanding and meaning. Part of this process is to incorporate the interpreter’s horizon or background beliefs. The term “horizon” is frequently referred to in research employing the Gademerian approach (Desalesturner 2003, Fleming *et al* 2003). Understanding the term horizon is therefore relevant and must be explored further.

Husserl’s ideas are based on horizons; as Gadamer comments: “*With this concept Husserl is obviously seeking to capture the way all intentionality of meaning merges into the fundamental continuity of the whole*” (Gadamer 1975) pg 57. For Gadamer the concept of horizons relates to things within our immediate world, meaning that our own particular viewpoint is constantly in the process of formation and is being shaped by our past and our awareness of the future (Desalesturner 2003).

Using the example of understanding sentences, Vessey (2010) clarifies the concept of horizons. Horizons can provide a perspective or a particular point of view and can be described as implicit and explicit beliefs:

*They establish what is significant understanding (those in the foreground) and what is insignificant (those in the background)....Horizons take on a particular point of view as the belief reflects individual differences* (Vessey 2009).

Another important aspect of Gadamer’s philosophy of understanding is what is described as the “fusion of horizons”. Horizons fuse when an individual realises how
the context of the subject matter can be weighted differently, leading to a different interpretation than initially assumed (Vessey 2009). This may be new information or a fresh understanding of the subject matter, and our horizons are broadened to form a better understanding. Even when there is no agreement about the subject matter, both parties will have reached this new shared understanding (Vessey 2009).

Gadamer also disagrees with Husserl that one is able to remain detached or neutral about an experience. He refuted the idea that the interpretation of a text aims at recovering the intentions of its author, but rather that we transpose ourselves into the perspective within which his views have been formed (Hans 1978). For Gadamer the key is “understanding”, and fore-structures, pre-understandings and prejudices are all important to the interpretation of language and texts (Gadamer 1975 pg 271).

Gadamer (1975 pg 273) explains what in essence fore-structures, prejudices and pre-understandings are, and how they may be used in the process of interpretation. Being aware of one’s own bias is part of this process, ensuring that it does not hinder understanding of the subject matter. For example, the prejudices we all bring to a situation from our past experience do not necessarily bring about a false judgement, indeed they may have a positive or a negative value (Gadamer 1975) pg 273. These pre-understandings are concerned with the same subject, so hermeneutics assumes that a person seeking to understand the subject matter already has a bond to it. He explains that the process of interpretation is not methodological and that the prejudices and fore-structures that occupy the interpreter’s consciousness are not freely at his disposal. This must come to light through understanding (Gadamer 1975 pg 274).

As an extension to his theory of interpretation and hermeneutics, Gadamer (1975) describes the hermeneutic circle proposed by Heidegger. This is essentially a movement taking place between the interpreter and the text.

*The point of Heidegger’s hermeneutical reflection is not so much to prove a circle but to show that this circle possesses an ontological positive significance...*
The constant process of new projection constitutes the movement of understanding and interpretation (Gadamer 1975) pg 239, 271:

This means that the interpreter must concentrate on “the things themselves”, a constant task in interpretation, so that a person is always projecting while interpreting. In doing this the text as a whole will begin to gain fundamental meanings, and every sentence or section can then be investigated to expose meaning and generate themes. These extracts are then related to the whole, and because understandings will change over time, this process could go on indefinitely (Fleming et al 2003). As Koch (1998) states, the hermeneutic circle is a metaphor for describing the movement between the part and the whole.

The keys to Gadamer’s philosophy outlined above are the fusion of horizons and dialogue, his provocative formulation of prejudice, and the circle of hermeneutics described by Heidegger (Koch 1999).

It is important to acknowledge another philosopher, Habermas, known to have debated with Gadamer, who developed what is known as critical hermeneutics. Habermas believed that to interpret and understand the way Gadamer takes into account tradition, background and history we must also look for hidden meanings which expose power relationships (Allen and Jensen 1990). For example, among our own prejudices race, gender and culture should also be critically interpreted (Koch 1999, Byrne 2001). Allen (1994) supports this view, arguing that hermeneutics is not adequate for nursing research since it does not take into account conditions such as organisational or ideological commitments that might have influenced participants’ description of their experiences.

Even with these views many nursing researchers have used Gadamer to underpin the philosophy for their research (Geanellois 1998, Koch 1999, Desalesturner 2003, Fleming et al 2003). I felt strongly that this philosophy was appropriate for the present research as it encompasses Heidegger’s philosophy, with the addition of deeper descriptions of how to incorporate prejudices and how to achieve a shared understanding through dialogue.
3.3.4 Paul Ricoeur (1913-2005)

Paul Ricoeur was a French philosopher who followed Gadamer’s description of hermeneutics (Ricoeur 1991, Ricoeur 1995). He emphasised that the way a text is interpreted is not a matter of understanding the intentions of the author but from the meaning of the text itself (Charalambous et al 2008). A term that has become associated with Ricoeur is “appropriation”, based on Gadamer’s concept of tradition. This relates to pursuing the meaning of a text beyond the author’s intentions, and also beyond the reader’s view of the text, thereby disclosing possible modes of “being in the world” that can be appropriated (Charalambous et al 2008). The result of this process provides the interpreter with a new perspective, which allows him to view the world differently (Charalambous et al 2008). Ricoeur (1995) also describes “distanciation”, in which the interpreter distances himself from any presuppositions and prejudices in order to pick up new meanings (Wiklund et al 2002, Charalambous et al 2008). Vessey (2010) suggests that this is where Ricoeur (1995) parts company with Gadamer and aligns himself with the view of Habermas in critical hermeneutics (Vessey 2010). Gadamer believed that Habermas was confused by regarding hermeneutics as not being critical enough, but that Ricoeur has followed Habermas and proposed this dialectic view of appropriation and distanciation, concepts he believed would lead to explanation and better understanding (Wiklund et al 2002, Vessey 2010).

Ricoeur concluded that narratives offer the best approach to investigating people’s lived experiences (Charalambous et al 2008). Lindseth and Norberg (2004) have developed a specific process to interpret texts using his philosophy, and this has been used in a number of studies of the lived experience (Lindseth and Norberg 2004, Lindahl et al 2006, Charalambous et al 2009, Dreyer and Pedersen 2009).

Since Ricoeur’s philosophy describes a distance from prejudices and almost uses Husserl’s view of bracketing, it was not deemed appropriate within the current study.
3.3.5 Maurice Merleau-Ponty (1908-1961)

Merleau-Ponty was another French philosopher, who in 1945 published *Phénoménologie de la Perception* (The Phenomenology of Perception). His phenomenology is existential, in the sense that it deals with people in a pre-given world (Sadala and Adorno 2002). In distinction to Heidegger’s interest in “being” Merleau-Ponty was interested in the science of human beings (Merleau-Ponty 1945:1962, Cohen *et al* 2000). He uses concepts of other philosophers, but more distinctively promotes the idea of perception and how the body can be viewed as the subject rather than as a separate object (Priest 2000). This may be due in part to the fact that Heidegger’s concept of being and the world did not address the issue of the body or embodiment. Merleau-Ponty’s preference for an existential and dialectical direction takes into account the human body and its action in a historical context (Kvale and Brinkmann 2009).

One of Merleau-Ponty’s (1962) central tenets that is popular with nursing scholars is his concept of embodiment. He proposes that the body is not an appendage or a thing in the Cartesian sense, and of particular relevance is the distinction he makes between “the body object” as “the body of medicine”, and “the lived body” or “body subject” as “the body of personal experience” (Thomas 2005). He takes the body as “self”, stating “I do not have a body, I am my body” (Merleau-Ponty 1945:1962, Sadala and Adorno 2002). This is particularly important when considering the relationship between the body and the world of a person who has become disturbed, for example during illness or disability, when that person’s existence is profoundly shaken (Thomas 2005). This has been described as a dialectic relationship between a person as a body and the world in which it is located (Sadala and Adorno 2002).

There are other aspects of Merleau-Ponty’s philosophy of interest in hermeneutics, in his description of perception. He focuses on the role of perception in the formation of awareness and experience, in which perceptions opens up to reality and provide a direct experience of the events, objects and phenomena of the world (Thomas 2005). This can mean that when new horizons of knowledge are reached during research, further questions can be asked to derive new knowledge and to seek more answers. So “People are eternally coming into being” (Sadala and Adorno 2002). The views of
Merleau–Ponty in relation to the body have not been described by the other philosophers and therefore would be relevant to the current study. Knowing the impact of CKD and that EPS posed an enormous threat to the ‘body’ I felt it appropriate to include Merleau-Ponty’s philosophy within the process of interpretation and analysis.

3.3.6 Phenomenology philosophers and their relevance to the present study

A discussion of the main figures in phenomenology and its philosophy provides the basis for understanding of where and how phenomenology originated, although this is mainly from a German or French perspective. They do not represent the entire range of views, of course, and there are many other writers who have contributed to the philosophical movement of phenomenology. Spiegelberg (1976), for example, dedicates two volumes entirely to the phenomenological movement (Spiegelberg 1976a, Spiegelberg 1976b).

More recently the American perspective on phenomenology has achieved prominence and there has been some criticism within the nursing profession that nurses have misused its philosophical concepts (Crotty 1997, Paley 1997, Paley 1998, Caelli 2001). On the other hand, Lawler (1998) has pointed out that phenomenology is the most universal qualitative research design used in the USA and that there is a strong Husserlian preference. The problems and criticisms arise when nurses describe a study as phenomenological and use bracketing – but then follow an interpretive existential method of analysis. The existential views of the philosophies outlined are not compatible with the idea of bracketing. Crotty concludes that what nurses are describing as phenomenology is not Husserlian, but is in fact a new phenomenology originating from American sources (Crotty 1997).

Hermeneutics aligned to the interpretive philosophy is recognised as an approach to health research which focuses on meaning and understanding (Charalambous et al 2008). The key to interpretive methodologies using hermeneutics is that they ask different questions and seek to know the world differently (Lawler 1998). Reference has already been made to the fact that Husserl’s (1913) descriptive phenomenology
was not appropriate, on the basis that the bracketing of any prior understandings or prejudices would not be possible. In line with the interpretivist approach, the theoretical frameworks of hermeneutics are used in the present study.

Hermeneutics has been described by a number of philosophers that can be applied to research. The key tenets of Gadamerian philosophy has been followed, as this fits closely with my own experience as researcher and nurse, and accepts that my prejudices, preconceptions and previous knowledge of the subject are brought to the research. The Gadamerian approach was also appropriate in that the participants had in all cases been living with a long-term condition for many years, and in order to understand the lived experience of EPS, it is not possible to separate it from the life world or context of their illness. The study focused on the meaning of the experience shared (with the researcher) by the participants and required a rich text from interview data to achieve this. The ‘circle of hermeneutics’ and ‘fusion of horizons’ (Gadamer 1975) described will be incorporated to achieve a shared understanding. In summary a Gadamerian approach was followed drawing on elements of Heidegger and Merleau-Ponty where appropriate, for example embodiment and temporality.

3.4 Applying hermeneutics to research methods

The philosophers mentioned do not propose a method for application to research, but merely offer a theoretical framework. It would therefore be mistaken to use all of them as the philosophical stance for research. The author’s philosophical positioning has been made clear, but applying this to the procedure once more required a critical appraisal of approaches given in the literature.

To overcome the problems facing researchers, many authors have used the theory of the philosophers named to choose specific techniques to apply to the research process. In the present study it was therefore decided to remain close to the chosen philosophy and incorporate a process of analysis that accurately reflected this. An overview of some of the current authors and procedures used specifically in hermeneutics is described and the rationale for chosen method for the study outlined.
Van Manen (1990) and his contribution to phenomenology is the basis of what has become known as the Dutch school. This is a combination of interpretive and descriptive phenomenology (Dowling 2007). Van Manen (1990) describes a clear process of phenomenological reflection, including the identification of meaning within the text, the role of the researcher and the process of phenomenological writing. Missing from Van Manen’s reflective approach, however, is how to deal with the pre-understandings and prejudices described by Gadamer (1975). Van Manen (1990) does in fact refer to the historical and social context of his interpretation, but only within the reflective writing process. An example of this is the way he describes the fundamental life world in terms of existential themes (Van Manen 1990, Van Manen 1997):

1. The lived space, or spatiality;
2. The lived body, or corporeality;
3. The lived time, or temporality; and
4. The lived other, or relationality.

These life worlds are referred to by other authors in the way hermeneutic research is presented, as they provide a lens to view the data (Munhall 2011). Van Manen’s (1990) work has been used in research by nurses to guide the analysis.

The “life world” approach developed by Dahlberg introduces additional aspects, known as “bridling”, suggesting that the researcher takes a more passive role and allows the phenomena to show themselves (Dahlberg et al 2009). Nurses have also incorporated team approaches to the analysis and interpretation, a move away from the philosophy of individual interpretation of text associated with hermeneutics (Diekelmann 1992). A method derived from Ricoeur (1995) uses a process in which reading of the text begins with immersion and a naïve understanding, followed by structured thematic analysis divided into units of meaning, sentences or paragraphs (Lindseth and Norberg 2004).

Two prominent approaches introduced by Giorgi and Colliazzi have been developed from a psychological perspective (Colliazzi 1978, Giorgi 1985, Giorgi 2006). There are
some differences between the two, however, and Giorgi (1985) bases his on Husserl’s (1913) descriptive approach and uses bracketing. Colliazi’s (1978) method, although stated to be derived from hermeneutics, parts company from Gadamer (1975) in the way it deals with pre-understandings. Colliazzi (1978) does not incorporate pre-understandings into the process of interpretation, but suggests that they can be used to formulate questions (Fleming et al 2003).

Some studies use a combination of these approaches, for example using Colliazzi’s (1978) stepwise approach initially, then following Van Manen (1990) at the second stage, which allows the researcher’s role and prejudices to be identified and allowed for (Clarke 1999, Evans and Hallett 2007).

A number of examples are given in the literature in which criticism and reviews of phenomenology have been put forward to provide examples of nurses applying the philosophy to the approach they use (Dowling 2003, Dowling 2007, Wojnar and Swanson 2007, Norlyk and Harder 2010). These examples prove helpful when designing a study and show that the researcher has to demonstrate the appropriateness of the chosen philosophy and how it has been applied to the research under discussion. It is also clear that there are many philosophers who describe hermeneutics and interpretation, and several sources are often used within a study. This is acceptable providing the sources do not have very differing theoretical or philosophical views, as for example has already been pointed out. Gadamer (1975) and Heidegger (1927) hold closely related views, however, and the two can be therefore employed within a single study. It is often difficult to identify approaches to research that use only one philosophy, but some nurses have achieved this (Benner 1985, Koch 1999, Desalesturner 2003, Fleming et al 2003). Following their example, in the present study a research approach has been applied incorporating Gadamer’s philosophy, based on the cycle of four steps described by Flemming et al. (2003). The only additional authors who have influenced the process are Van Manen (1990), who offers an actual method, and Merleau-Ponty (1945), who addresses the concept of embodiment. These will be described within the findings.
3.5 The methodological approach to analysis

The philosophy of the study and the type of interviews has been described so far. These were based on the original aims and objectives of the study. Flemming et al. (2003) emphasise that “research carried out in a Gadamerian tradition is developed from a desire to achieve a deep understanding of a phenomenon”. It is also important that during the research process both the researcher and participants remain orientated to the subject under study. As indicated earlier, in writing the reflexive journal my own pre-understandings became clear, and began the process of interpretation. The following four steps have been identified for the procedure used in the present study. They are based on Gadamer (1975) and the work of Flemming et al. (2003), and follow data collection. They are not exclusive, and may not always follow this sequence (Fleming et al. 2003):

1. The text as a whole is examined to gain a sense of the initial understanding.

2. Every sentence or section is examined to expose its meaning in order to understand the subject matter. Early themes may become apparent at this stage.

3. Every sentence or section is then related to the whole, described as a movement between the parts and the whole, an essential component of the hermeneutic circle.

4. It then becomes possible to begin to identify where a shared understanding has been achieved between researcher and participant.

This process could go on indefinitely, and although it seems simple it is actually complex and time consuming. The specific process of how the findings and themes were arrived at will be discussed later. Suffice it to say trying to find the themes was a long and difficult process, but the reader needs to understand that:

Making something of a text or of a lived experience by interpreting meaning is more accurately a process of invention, discovery or disclosure. Therefore the concept of a theme maybe irrelevant but it gives control and order to research and writing. (Gadamer 1975, Van Manen 1990)
In developing themes there has always to be a questioning process, not only of the
text but of oneself as a researcher, in order to gain the shared understanding that
Gadamer (1975) advocates. Processes of interpretation may differ between studies,
often in respect of whether or not a researcher should go back to the participants for a
second or third interview. Again there is some debate, and Gadamer (1975) has made
it clear that trying to put oneself in the other person’s shoes is not the purpose of
interpretation, although going back to the participants may imply this. Other
researchers agree with this, arguing that interpretation should be based on the text
alone rather than the participant’s understanding of it (Ricoeur 1995, Geanellos 1998).
In the interpretive dialogue between the text and the interpreter resides the fusion of
horizons.

The opinion of Van Manen (1990) is that going back and forth to the participant is in
fact a feature of the reflexive process. As the researcher is an element in the process,
deeper meanings can be achieved through this reflexive process. Fleming et al. (2003)
also advocate this on the basis that understanding depends on a particular historical
situation, and that the understanding of the subject matter and the understanding of
the researcher will change over time. In order to facilitate the circle of understanding
the initial interviews should be analysed first and then an initial summary given to the
participants in preparation for the second interview (Fleming et al 2003). Other
authors support this, for instance in Clark’s (1999) study of motor neurone disease she
explains clearly how through her own prejudices and understandings she was able to
formulate significant statements and then go back to each individual participant with
these first-level themes. In my own case I decided that a second interview would be
carried out, and if necessary a third, if time permitted. This would allow a process of
shared understanding. Since Gadamer (1975) did not suggest the actual methods, this
is perhaps one aspect of his philosophy that has had to be manipulated in health
research. It made sense for me to go back a second time; I avoided the term “member
checking” as part of this process as I wanted to ensure the participants were part of
the interpretive process in order that we could achieve a shared understanding.

The actual interpretive process and how the data were managed will be described in
Chapter 4.
3.6 Ethical considerations and research governance

Full ethical approval was obtained before the study began from the Central Manchester Ethics Committee, and university ethical approval and research governance approval was provided by the Central Manchester Trust. Before data collection took place participants were asked to read a patient information sheet and to sign a written consent form. Copies and storage of these documents followed the governance procedures determined by the Trust and university policies.

The qualitative process of in-depth interviewing can be an area of concern. Difficult and emotional issues may arise and, should these occur, I had to ensure that access to psychological support services was available. Sensitivity to patients’ health needs and their level of illness required careful thought and planning, and my own professional experience was an asset.

Clarke (2006) points out that during distressing moments it is vital that the researcher acts professionally and with empathy. This entails avoiding probing when it is not necessary, and offering to stop the interview (Clarke 2006). As an experienced clinician previously working in the community, issues surrounding home visits and respect of the individual were readily appreciated. I attended lone worker policy training at the university to prepare for working on my own during data collection.

Considerations of transcripts and recording equipment are also an ethical concern, in order to ensure that confidentiality is maintained throughout the study. All transcribed data were coded to prevent participants being identified. Those undertaking the transcription were from an outside agency recommended by the university and undertook to maintain confidentiality. All data were entered into software specific to qualitative analysis, but no names or identifiable data were used unless password protected, and the data were kept securely locked in a drawer in the researcher’s office. I also had to consider how data might be used in future presentations or at conferences. Due to the rarity of the condition and the fact that only two centres in the UK offer surgery, it might be possible to identify individuals on the basis of their length of time in hospital. Reassurance that these elements would be omitted if the results are presented within the specialty arena was important.
The role of the researcher during the interview is also important from an ethical perspective. Acting professionally and ensuring integrity throughout helps to maintain trust on the part of the participants. This has been discussed in the previous section. The participants need to feel relaxed and at ease with the process to ensure they are able to talk freely, but be aware they are placing some details in the public arena.

Another aspect of ethical concern is the process of informed consent. Informed consent is a requirement of research in order to ensure that participants understand their role and to confirm confidentiality and anonymity. A copy of the informed consent is provided in Appendix 3.

Participants’ renal consultants and their GPs were also contacted to inform them (copies of these letters are shown in Appendix 4). In addition to forming part of the governance requirements of the study, this also ensured there were no significant medical issues that I should be aware of before I interviewed the participants.
Chapter 4.0: Applied Methods

The applied methods provide an overview of exactly how participants were recruited and accessed, the data collection methods with a summary of how the interpretive process was followed.

4.1 Sampling criteria

These form the first part of the process, to indicate which population would be approached and regarded as suitable for the study.

4.1.1 Inclusion criteria

- Adult patients 18 years and over who have been diagnosed with EPS; and
- Diagnosis accepted on the basis of surgical intervention performed in Manchester.

4.1.2 Exclusion criteria

- Non-English speaking participants (on the basis of practical issues related to interpreter costs); and
- Patients referred from outside the UK.

4.2 Sampling principles and procedures

Sampling must accurately represent the population under study. The sampling procedures available for qualitative research include a range of techniques under headings such as snowballing, theoretical, convenience and purposeful, although this list is not exhaustive (Miles and Huberman 1994, Bowling 2002, Higginbottom 2004,
Holloway and Wheeler (1996). Sampling procedures must be guided by the underlying philosophy, the research aims and the population required for the study.

Theoretical sampling is used in grounded theory approaches and is based on the fact that as the study progresses analytical steps that generate new emerging themes requires further sampling, until theoretical saturation occurs (Higginbottom 2004). This was not appropriate for the present study based on the assumption that the study did not aim to develop theory from the data. Snowballing is used when a previous participant is asked to suggest other informants or potential participants relevant to the chosen subject. Again this could not be used in this current study.

Purposeful sampling was therefore used, since as (Bowling 2002) pg 187 notes:

This is a deliberately non-random method of sampling and aims to sample a group of people or settings having a particular characteristic, usually in a qualitative research design context.

This is therefore a process requiring a conscious decision to recruit participants relevant to the phenomena under study. Firstly, the participants selected had to have undergone surgery for EPS, which is a rare condition and makes them unique. Usually sampling procedures have to ensure that an adequate representation of the population under study has been accessed, but with only a small number of patients undergoing surgery each year the group was already defined. Applying the principle of heterogeneity was not relevant due to the small numbers meeting the inclusion criteria. Patients available for the study would therefore be determined by referral patterns and the number of surgical procedures taking place during a given time frame.

The Renal Unit in Manchester Royal Infirmary is one of only two in the UK at present funded for surgery specific to EPS. In this centre one specialist surgeon had operated on 50 EPS patients during the year preceding the study.

Based on an initial review, and allowing for a 50% drop-out or refusal rate, a total of 30–40 qualifying individuals across the UK should yield a sample size of 10–20 participants. I took the decision that once the study started I would give consideration to patients who had undergone surgery and had been discharged from hospital during the preceding three months. This decision was based on the fact that many patients
had extended lengths of time in hospital. If I had begun recruitment only at the one year start point of those who underwent surgery at the same time point, they potentially would only be discharged six months into the study period. As I wanted to conduct the interviews once they had been discharged, it would not have been possible to complete all the interviews within the study timeframe.

In qualitative work small numbers are not necessarily regarded as a problem – in fact there is little consensus about what is acceptable (Holloway and Wheeler 1996). As has often been stated, “thick descriptions” are the essence of this type of research and criticism often arises when the sample size is too large and the “richness” of the data may be lost (Holloway and Wheeler 1996). After the initial interviews it was clear that this was not an issue, and this will become apparent from the findings.

4.3 Gaining access

The locating of suitable patients was assisted by the presence of a consultant surgeon in Manchester to whom patients from other centres had been referred once diagnosis of EPS was found to require surgical intervention.

Potential participants were initially contacted after surgery by letter, enclosing an information sheet (appendix 5) explaining the background to the study. After two weeks they were contacted by telephone.

All participants were to undergo two interviews; this would generate 18 transcripts of interview data. They were each interviewed in their own homes, the choice of all the participants.

4.4 Data collection methods

For research purposes, lived experience is collected through narratives provided by participants. These are converted to text, and this always then needs to be interpreted (Lindseth and Norberg 2004). The use of interviews was chosen, since not only do these determine the questions posed, but they also embody the underlying philosophy.
The purpose of the interview is as far as possible to obtain “thick” responses to the research question, by allowing participants to talk freely about their experiences. For the present study considerable preparation was given to the conduct of the interview, both in terms of the basic philosophy and also the skills required. I wanted to enter this process with an open mind and had many discussions with colleagues, including a counsellor within the department where I am employed. This allowed time to reflect on specific approaches and conduct for the interview, and to develop the skills needed.

Generally speaking, three types of interview are in common use:

- Structured, which are closely linked to survey studies;
- Semi-structured, using an interview guide; and
- Unstructured interviews.

Unstructured interviews are used in the present study. These are associated with grounded theory and phenomenological approaches, which allow “thick” descriptions of data collection. Interview types have also been described as active, interactive, open-ended and conversational (Silverman 1997, Cohen et al 2000, Kvale and Brinkmann 2009). The questions used in unstructured interviews can be guided by topics and open questions. In this study the initial open question to the first interview was:

_Tell me about your experience of EPS_

The aims of the study should always be at the forefront of an interview, and I was able to apply the principles of a hermeneutic interview as described below.

4.4.1 The hermeneutic interview

The initial use of an open question is a feature of the hermeneutic approach to interviewing (Lowes and Prowes 2001). Once the participant had answered this first question I was able to ask more specific questions to obtain clearer, richer and deeper descriptions. I then used the objectives of the study as a guide for the interview. Some authors have described the hermeneutic interview as the ability to keep oneself free to
go on asking questions (Johnson 2000). Specific techniques such as probing and using questions are suggested by Sorrel and Redmond, for instance (Sorrell and Redmond 1995):

- What does this mean to you?
- How were you feeling at the time?
- Tell me more about that.

These probes were used in both interviews. Silences can form part of the interview and must be allowed to happen without feeling uncomfortable, especially when difficult and emotional issues are being described. Sometimes words are not enough.

These are crucial points, since having identified the interviewing technique as unstructured there is a danger of generating mountains of data that are both unmanageable and do not answer the research question. Advance preparation and focus are therefore essential, in addition to decisions about the recording equipment and the transcription and management of the data. All of these issues were addressed and will be described later in the chapter.

The aim of the interview is to uncover meanings, the whole interview seeking to understand the central themes of the subjects life world (Kvale and Brinkmann 2009). The entire interview is therefore concerned with describing the world as experienced by the subject, and contains the underlying assumption that reality is in fact what people perceive it to be. By blending, then listening and being a co-participant, I was able to explore and share new meanings (Sorrell and Redmond 1995, Kvale and Brinkmann 2009).

Kvale and Brinkham (2009) make the point that the interviewer needs to be knowledgeable about the subject area, to be observant and sensitive to the specific language and vocalisation used by the participant. Observing body language, gestures and facial expressions are all important. This was particularly relevant to the present study, since the topic area is complex and participants needed to feel reassured that the interviewer was familiar with it. On the other hand, it is equally important to remember that no matter how at ease the participants are, there is inevitably an
imbalance in the relationship between the researcher and the participant. Being aware of the researcher’s own prejudices is fundamental to the interview process and to achieving a shared understanding.

During the study a second interview was also conducted. Going back to the participants after the first interview with a summary of initial themes and interpretations helped the hermeneutic process. Since the interviews relied on a retrospective perception of the experience, the second interview allowed the participants further time to reflect. This has been argued to lead to enriched data, as participants can add further narratives (Cohen et al 2000). The interviews therefore began with interview one as unstructured, using an open question as described above. The second interview was conducted following a written summary of my initial interpretation being sent to each participant. The second interviews used this summary as a prompt to guide the interview, including the specifics of the objectives of the study as a guide (see appendix 7). Section 4.5 will describe the processes involved.

4.4.2 My role in the interview

In reflecting on my own role I had to consider how the participants might choose to represent themselves and how much information they would be prepared to disclose.

An interviewee’s response is influenced by factors such as social class, professional status, gender and age (Silverman 2000). To obtain the “truth” during an interview a response which fully represents the feelings and emotions of the interviewee can be difficult. Participants may only present a “public account”. All of these factors, and recognising that there was an imbalance in the relationship made me consider my approach very carefully. Many of the participants knew me only as a nurse undertaking a study, and they did not know my background. To overcome these issues before the interview began, some simple introductions and general conversation were important. This establishes a level of trust and allowed participants to feel relaxed before the interview took place.
Deciding how much to reveal during an interview has to be considered in advance. I decided not to be too prescriptive but to remain aware of the issue. Other authors have discussed this aspect and acknowledge that it is impossible to leave one’s clinical role out of the interview (Borbasi 1994, Carolan 2002, Clarke 2006). Reciprocity is one way to consider this tension, defined by Carolan (2002) as “the practice of exchanging things with others for mutual benefit”. This acknowledges one's role, not just as a researcher and clinician, but also as a human being, a woman and a participant in the process. These issues will be dealt with in more detail in discussion of reflexivity within the study.

I knew three of the participants in advance of the interview, but still had to think about my approach. I wanted them to see me as a researcher, but I knew these participants would retain their picture of me as a nurse. The other participants all lived at a distance from the hospital; I travelled by train and car.

A number of other issues were considered before the interview, including what I should wear, where the tape recorder should be placed, how emotional or difficult issues would be dealt with, and the need to be aware of my body language. Essentially I wanted participants to feel relaxed and at ease. I was well aware of the frailty of the participants, some of whom were still recovering, and the time frame therefore had to be considered. I did not want the participants to become overtired by the interview. My biggest concern was with the participants I had not met previously and who lived a long distance away. However, as an ice-breaker one participant met me off the train, and on other occasions I sometimes made phone calls en route to ask directions.

In the hermeneutic approach to interviewing, the interviewer is a co-participant and is an essential part of the interpretive approach (Lowes and Prowes 2001).

4.4.3 The reflexive journal

I have purposely chosen the term “reflexive” in place of “reflective” as the two have different meanings. A reflective journal is not specific to research and can be used by individuals to write down reflections on a number of issues, for example one used in education to document learning experiences (Dasgupta and Charon 2004). Reflexivity
in research is a more specific concept, as it acknowledges the role of the researcher and the situated nature of the research (Jasper 2005). That is not to deny that it may sometimes be reflective in nature, but the purpose is to demonstrate how as a researcher I approached the study reflexively.

Reflexive writing is an aspect of this type of research, and also of other types of qualitative research (Carolan 2002). It acknowledges the subjective nature of the researcher’s interaction and interpretation of the data, providing a decision trail within the domain (Jasper 2005). Jasper also shows how reflexive writing becomes part of the analytical process. A reflexive journal can have multiple purposes in qualitative research.

The process of interpretation inevitably began before the interview, at which time I identified my own pre-understandings and prejudices. This included reflexively identifying my own position within the project before beginning the data collection. The reflexivity process continued with completion of diary entries after each interview, including feelings, reactions and nonverbal observations during the interview. I also used this approach to write down my own thoughts and feelings, particularly when my own prejudices were questioned. The process of reflexivity is continuous, but also provides evidence of an audit trail, which is particularly important for this type of research and is recommended in hermeneutic phenomenology (Koch 1996, Koch 1999, Smith 1999). Further discussion of this will be provided in the section addressing the quality of the study.

Van Manen (1990) also describes the process of reflexive writing, comparing the process of writing to literal and epistemological silences. These often occur when words or language cannot express true meanings, and a silence may mean that something is unspeakable. The same can be true during the process of writing, and when faced with the unspeakable other, or borrowed, language may be used (Van Manen 1990). As Gadamer (1975) states, truth can have different meanings in the different linguistic communications we use. Writing within the journal was a process of self-awareness and I would often read through the entries to assess my thoughts about particular interviews and extracts. This process was self-reflective and critical,
and I had to examine my own prejudices on the way I was interpreting and presenting the findings.

Extracts from the reflexive journal were then used in presenting the findings; this allows the reader to see where and how decisions were made and identify potential influences, but more importantly how a shared understanding was achieved. Reflexivity as a process has also been used to describe the tensions between the role of the researcher as a clinician during the interview process (Carolan 2002). This was particularly personal in my own case as I had a role as clinician and a number of years’ experience within the subject area, and had been responsible for the care of several of the participants I would be recruiting.

The dichotomy is that Gadamer (1975) advocates that the interpreter be knowledgeable of the subject, and Johnson states (Johnson 2000) that:

...in order for the interpreter to understand what is going on he/she must share the same general human background understanding of the group being studied.

To overcome what may be seen as problems within the research process I had to be aware of the strengths and limitations of my own experience in dealing with the complexities of the phenomena under study. This became evident in the questions the participants asked during the course of the interviews.

4.5 Collecting and managing the data

4.5.1 Time scale

The data collection period was between October 2009 and October 2010. All interviews were conducted within this time frame.

4.5.2 Transcription

The choice of an outside agency to transcribe was a practical decision. It was the appropriate procedure since the interviews would probably be lengthy and transcription time-consuming. Funding was secured to enable this to take place.
4.5.3 Computer Software

In deciding how to manage and organise the transcripts, there were two main considerations. Firstly organising data manually, moving data through cutting and pasting within documents using word processing facilities. Computer software packages are also available, designed for managing interview transcripts. Having used Nvivo before, I felt comfortable with using it for this study. I only used it the initial stages of the process of analysis, as will be described in the next section. I still used manual methods to create a chart to organise some of the initial headings, this provided a visual display of how the study findings were formulated into themes.

4.6 Interpretation and analysis

The process of analysis and justification of theme development has been described in section 3.5. The specific process of how the findings were organised and interpreted are now described.

4.6.1 Organisation and interpretation

Table 4 Summarises the procedure adopted (Fleming et al 2003).

Table 5 Procedure Followed for Analysis

<table>
<thead>
<tr>
<th>Process</th>
<th>Actions taken</th>
</tr>
</thead>
<tbody>
<tr>
<td>First individual interview</td>
<td>Played back and began writing in reflexive diary</td>
</tr>
<tr>
<td>Interviews transcribed</td>
<td>Read through transcriptions, checked and made further notes. Began making</td>
</tr>
<tr>
<td></td>
<td>headings and adding statements to NVivo</td>
</tr>
</tbody>
</table>
The initial stage in the analysis involved replaying recordings of the interviews and examining the text to gain a sense of the data as a whole. Some initial thoughts were extracted, and meaningful statements were listed using the NVivo software. Meaningful statements were direct quotes of either sentences or single words, and these were organised under suitable headings. This helped to classify the data, but it was necessary to reread and listen to the interviews again, noting my own reflections as I went along. These were recorded in a reflexive journal.

Going back and forth to the transcripts to develop understanding and to guide future interviews is an essential part of the hermeneutic process (Johnson, 2000).

For each participant I wrote a summary of my interpretations from the first interview. These provided an individual approach to the meaning of the experience; however it soon became clear that a number of common themes were emerging. For most of the participants the headings were thus quite similar, but at this stage it was not clear whether these would remain the main themes and a period of contemplative writing was necessary. I then focused on the second interviews. Taking from these a sense of
the whole and how this had gradually evolved, it was possible to use my interpretations to arrive at a meaning for the entire experience.

In assessing the second interviews a similar format was adopted as for the first, all the meaningful statements being listed (Appendix six) and allocated under existing headings, or if necessary new headings were developed. My initial reflections were expressed in the themes as a time-line (Appendix seven). This was similar to the way the initial interpretations were presented to the participants and it confirmed the validity of the approach adopted.

However, thematic analysis is, as (Van Manen 1990) states, “not a ruled-bound process but a free act of seeing meaning”. It is more a thoughtful and reflective process. Or as has been indicated here:

\[
\text{The differential between methodological sterility and genuine understanding is “imagination”, that is, the capacity to see what is questionable in the subject matter and to formulate questions that question the subject matter further (Gadamer 1975).}
\]

Reflecting further on the interview text, which is part of the hermeneutic circle, I needed to introduce my own perspectives and demonstrate how the shared understanding was developed – a process of challenging my own pre-understandings (Fleming et al 2003). Remaining open to the text, and trying to see beyond what was actually written, I therefore focused on the major themes, each with sub-categories, all of which were explicitly interrelated.

These themes were developed from the meaningful statements obtained during the first and second interviews. In order not to lose the essence of the phenomenological approach in interpreting individual meanings, even within the themes, individual experiences have been described. This is a shift away from universal meaning. As Munhall argues, this collapses the language and doesn’t provide the individual understanding associated with phenomenology (Munhall 2011). However, from a practical approach there were occasions when the words used by the participants were similar when describing their experiences. After this stage was complete, when most of the findings had been written, I approached two participants with a
representation of the themes as they have been presented in a graphical form (see Chapter 5).

The next phase was perhaps the most difficult. Having reached a stage where I considered that I had represented the participant’s views and meanings properly, I found that the research aims had constantly to be considered. The dilemma was to condense and collapse large areas of the findings that overlapped. In some places there were lengthy findings which, although important, fell outside the main messages arising from the study. I was conscious of the vast amount of data now available and was anxious not to lose what appeared to be essential meaning. I chose to include direct quotes from the interviews, verbatim and without any changes. This would give a sense of the nature of the conversation, and would also allow silences or emotions to be included.

4.7 Reflexivity and quality

The methodology and philosophy for this study has been identified as that of hermeneutics derived from phenomenology; incorporating a Gadamerian approach to interpretation. As with all research projects the issues surrounding good quality research are based on the processes being adhered to in what may be described as a rigorous manner. In quantitative research this traditionally refers to validity, reliability and generalisability. These terms have been contested by many authors as inadequate, and not being applicable to qualitative research (Sandelowski 1986, Sandelowski 1993, Koch and Harrington 1998, Cutcliffe and Mckenna 1999, Koch 1999, Cohen et al 2000, Pope and Mays 2000, Maggs-Rapport 2001, Cutcliffe and Mckenna 2002, Rolfe 2006, Porter 2007). This debate has led to some difficult arguments about how the quality of a piece of qualitative work should be assessed. While most academics agree that the terms used in quantitative research cannot be applied to qualitative studies, there are perhaps two aspects to the debate. There are some who see qualitative work as adopting an aesthetic and rhetorical approach that may be subjected to evaluation and appraisal (Sandelowski 1986, Sandelowski 1993, Rolfe 2006), and others who apply
more orthodox terms such as rigour, but at the same time advocate reflexivity and the clarity of an audit trail.

Watson and Girard (2004) use a Gadamerian approach to analysis, similar to the present study, and discuss the use of integrity as a suitable term to describe scientific adequacy. To them the term integrity denotes wholeness, honesty and soundness. Wholeness encompasses the hermeneutic circle of researcher, participant and understanding, and should be clearly demonstrated throughout the interpretive process (Watson and Girard 2004).

The purpose of providing evidence of quality is so that readers can follow the way in which the author arrived at his interpretation of the data (Koch 1996). Even within hermeneutic research, where the researcher is a co-participant, influences of bias, relationships and social processes need to be reduced as far as possible. This is not to say that the researcher becomes objective, but through the analytical procedures evidence of these factors needs to be present and discussed, particularly in regard to the influences on the interpretation. This all relates to the hermeneutic circle and the researchers’ own prejudices. To achieve this I chose to include exerts of the reflexive journal in the presentation of the findings.

Koch (1996) sets out criteria written by Guba and Lincoln and is based on the trustworthiness of a qualitative inquiry (Koch 1996). The criteria identified will be used as headings, and will incorporate other recommendations applicable to the current study.

**Credibility** is an evaluation of how the findings of the study are credible, and are based on credible methods (Shenton 2004). Credibility is also described as accuracy. The philosophy and methods used during the present study were described in detail in Chapter 3. The findings, given in Chapter 5, should confirm its application and demonstrate the accuracy obtained. To demonstrate the self-awareness aspect, I have used extracts from the journal and shown how critical reflection has been applied, a method advocated by others (Khan et al 2007, Smith 1999). At the beginning of this study I wrote a critical reflection and continued the process throughout by use of a journal and field notes. This will be presented at the beginning of Chapter 5.
Reflexivity is used often to describe this process and the following definition given by Carolan summarises the concept well (Rice and Ezzy 1999, in Carolan 2002):

Reflexivity is an acknowledgment of the role and influence of the researcher on the research project. The role of the researcher is subject to the same critical analysis and scrutiny as the research itself (Rice and Ezzy 1999).

In the present chapter issues of the role of the researcher have been alluded to, in one case as researcher and in another as clinician, and how reflexivity was approached. To ensure credibility is maintained, all of these issues need to be visible and how they have been dealt with demonstrated in the analysis and interpretation.

Transferability is the degree to which the findings of the study can apply or be transferred beyond the limits of the project (Shenton 2004). This is perhaps more difficult to achieve in some qualitative work than others, but it refers to the appropriateness of the results. It depends upon the degree of similarity between two contexts but should provide sufficient contextual information to make similar judgements possible (Koch 1996). In the present study, evidence of this will be described in the discussion, using the findings of the study and how they can be applied.

Dependability refers to the audit process, sometimes referred to as an audit trail. This is to ensure that all methodological and analytical decisions made throughout the study are properly documented and described. Cohen refers to this process as “opening up the inquiry” (Cohen et al 2000), and includes the documentation of decisions and the strategies that have been employed. This may even include discussions with research groups or colleagues and supervisors. Checking the accuracy of the transcriptions is also essential and can only be achieved by reading them while listening to the interviews. The description of an audit process should not be misconstrued as another person looking at the results and arriving at a different interpretation. Each qualitative researcher has a unique relationship with the data, and other researchers may not necessarily uncover the same findings (Sandelowski 1998). The audit process referred to here is how I can clearly describe the decisions made,
and use of the reflexive journal and the interview extracts should convey this to the reader.

One way of ensuring accuracy is “member checking” (participants are invited to check the accuracy of the interpretations or even read the interview transcripts) as part of this process, and this can be either formal or informal (Watson and Girard 2004). As described earlier, I chose to conduct a second interview. The rationale for this was to ensure that the initial interpretations were representative, but also to allow the participants to add any new knowledge. It was also an opportunity to ensure that a shared understanding had been achieved, following other researchers’ recommendations, as it enables the hermeneutic circle (Sorrell and Redmond 1995, Fleming et al 2003).

Confirmability has been described as another component of quality, once credibility, trustworthiness and dependability have been achieved (Koch 1996, Koch 1999, Shenton 2004). For the present study in particular the truthfulness and trustworthiness of the data relate not just to the results but equally to the process. According to Gadamer, in interpretive studies there can be no statement that is universally true, because no statement can escape the complexities of interpretation (Fleming et al 2003). The essential aspects of movement from the whole to the parts should be clearly documented to demonstrate understanding of the phenomena.

The criteria described in the four processes give an overview and plan of how it has been applied in the present study. Many of the issues have been addressed in Chapters 3 and 4. However the other issues will become evident in Chapters 6 and 7, Findings and Discussion, and the exact issues that need to be explained to the reader will finally be described. This will help to confirm the authenticity of the study and the relevance of the new knowledge generated in clinical practice. No previous research has been reported into the patient experience of EPS, and clinical practice will clearly benefit from the new approaches to care and management now identified and discussed (Chapter 7).
CHAPTER 5: FINDINGS

5.1 Introduction

The purpose of this chapter is to present and critically discuss the findings of the study. The characteristics of the participants will be outlined, and then findings will be presented under their themes and will then be discussed in Chapter 6. The participants in this study had already experienced a “life world” dominated by dialysis, including adjustment to a long-term condition and trying to maintain normality. They used the language and descriptions expected of patients who are knowledgeable about their illness.

5.2 The participants

5.2.1 Recruitment

The sample size was estimated as 10–20 participants. During the period of study a total of 18 patients underwent surgery, but only 11 were suitable or eligible for inclusion. I also recruited from those who had undergone surgery before October 2009, as described in Chapter 4. One possible participant declined, and one who had previously agreed became unwell before the first interview and was not included. Two were sent letters and I was unable to make contact, the others were too far geographically either outside England e.g. Scotland or Ireland or even from Europe. Nine participants in total were finally recruited for the study.

5.2.2 Details of the Participants

The geographical spread of the participants ranged from East Midlands to Northwest England. The age range was quite narrow, the mean age being 51 and the range 45–56 years. The average age for starting dialysis in the UK is given as 65 years (Renal Association 2009), indicating that the participants in the present study were relatively
young. This may reflect the fact that it is more often younger patients who are undertaking home dialysis.

It is important to understand the procedure through which the participants’ past experiences were brought into the research. The summary that follows provides the background for each participant, including their circumstances and experience. It also gives a link to the findings, in which pseudonyms are used in line with ethical principles. All the interviews took place in the participants’ homes, at their request.

Table 6 provides demographic details, the interview plan, length of stay in hospital and the current dialysis modality status of the participants (N.B pseudonyms have been used). Sadly, it will be seen that three of the participants have died during 2011 since completing the study; one of the deaths was EPS-related, one a recurrence of cancer and one a cardiovascular event.
<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Gender</th>
<th>First interview (mins)</th>
<th>Second interview (mins)</th>
<th>Interval between interviews (weeks)</th>
<th>Time in hospital (weeks)</th>
<th>Current modality status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beryl</td>
<td>51</td>
<td>F</td>
<td>63</td>
<td>48</td>
<td>15</td>
<td>20</td>
<td>Mhd</td>
</tr>
<tr>
<td>Michael</td>
<td>45</td>
<td>M</td>
<td>98</td>
<td>80</td>
<td>15</td>
<td>24</td>
<td>Mhd</td>
</tr>
<tr>
<td>Barbara</td>
<td>54</td>
<td>F</td>
<td>50</td>
<td>48</td>
<td>12</td>
<td>28</td>
<td>RIP</td>
</tr>
<tr>
<td>John</td>
<td>53</td>
<td>M</td>
<td>55</td>
<td>34</td>
<td>9</td>
<td>5</td>
<td>Mhd</td>
</tr>
<tr>
<td>Nicola</td>
<td>47</td>
<td>F</td>
<td>35</td>
<td>n/a</td>
<td>6</td>
<td>Tx</td>
<td></td>
</tr>
<tr>
<td>Simon</td>
<td>56</td>
<td>M</td>
<td>56</td>
<td>67</td>
<td>14</td>
<td>20</td>
<td>Hhd</td>
</tr>
<tr>
<td>Annette</td>
<td>53</td>
<td>F</td>
<td>48</td>
<td>38</td>
<td>12</td>
<td>3</td>
<td>RIP</td>
</tr>
<tr>
<td>Mary</td>
<td>49</td>
<td>F</td>
<td>60</td>
<td>35</td>
<td>12</td>
<td>4</td>
<td>Hhd-Tx</td>
</tr>
<tr>
<td>Cheryl</td>
<td>51</td>
<td>F</td>
<td>64</td>
<td>41</td>
<td>8</td>
<td>4</td>
<td>RIP</td>
</tr>
</tbody>
</table>

Key:  
Mhd: Hospital based haemodialysis (maybe satellite unit)  
RIP: Died  
Hhd: Home hemodialysis  
Tx: Transplanted  
Hhd-Tx: Home haemodialysis and then transplanted
5.2.3 The individuals themselves

**Beryl**

Beryl is a 51-year-old lady living 150 miles from Manchester and is married with one son. She had been on PD for eight years but was on satellite HD when she developed EPS. I did not know Beryl before the interview. She requested that her husband was present during the second part of the first interview. She had been in hospital for four months and had experienced a number of complications. Her husband joined us for a short period at the end of interview one, at the request of Beryl. At the second interview, she had clearly improved physically and was feeling much better. She had read the summary I had sent and had made notes on the issues she wanted to ensure were covered.

**Michael**

Michael is 45 years old and lives with his wife and a son aged 16. He had been on PD for six years and was diagnosed with EPS when he transferred to HD. I had not met him before the interview as he lived a considerable distance from Manchester – indeed a number of phone calls were required before I was able to find his home, and this helped to break the ice when I eventually arrived. He had been diagnosed with EPS following an urgent admission to hospital and he remained unconscious in the Intensive Treatment Unit (ITU) for five weeks. He was transferred to Manchester from his local ITU and his first conscious recollection was waking up in Manchester. He had been on satellite HD before admission. The first interview was very long, during which his wife joined us – in fact she did most of the talking.

**Barbara**

Barbara was 44 years old and married with three children. She lived a long way from the hospital, a total distance of 90 miles. She had been on PD for more than 12 years before switching to HD and went through a year-long period of illness before
undergoing surgery for EPS. She had been in hospital for six months and had experienced a number of complications.

Our first interview left me feeling quite humble after listening to what she had been through, and I detected that she was still weak and possibly vulnerable. During the second interview she was again very open and felt able to talk about some very difficult issues that were still causing her distress. She mentioned that she had now split from her husband and was considering moving back to her home town.

Sadly, Barbara died in March 2011.

John

John is 53 years old and lives at home with his wife; he has three children and three grandchildren and lives more than 70 miles from Manchester. He had been on PD for five years and was diagnosed with EPS after an acute episode of peritonitis. He is currently undergoing HD at a satellite unit. He had been in hospital for five weeks, with no serious complications afterwards. John frequently employed humour during the interview and tended to wander from the subject; he used anecdotes and often referred to his past. He contacted me after both interviews had been completed to let me know that he had had a recurrence requiring further surgery.

Nicola

Nicola is 47 years old. She is married with one son and worked full-time as a nurse in mental health. She was the only participant who had suffered from EPS following kidney transplantation, having been on PD for eight years before the transplant. I had not met her before the interview. Once I had stopped recording she continued to talk, particularly about her religious faith and how it had helped her through the whole experience. I did not want to omit what was clearly an important aspect of her experience, and as soon as I left I made notes and recorded my own recollections of what she had said. She also wanted to talk about her husband, who had been ill at a different hospital during the time she was undergoing surgery. Unfortunately he died
before the second interview. I attempted to contact her, and although she sent an e-mail telling me about this, the second interview did not in fact take place, as I had the feeling it might be too much for her.

**Simon**

Simon is 56 years old and lives with his wife. They have three children and five grandchildren. He had suffered from kidney disease for 30 years and had experienced all types of dialysis, HHD and PD. He had also had a transplant. He therefore brought a vast amount of experience to the interview. I already knew Simon as a patient when he was undergoing PD and we had developed a good relationship. He underwent surgery five months before the interview, spent two months in hospital and had been at home for a further three months. He had been readmitted on a number of occasions with complications relating to EPS.

Since the interview he has remained in contact and has kept me informed about his progress. He is very keen to hear how the present study will influence future practice. He has now been successfully trained in HD and is carrying this out at home, although he frequently continues to be admitted with ongoing problems related to his surgery.

**Annette**

Annette is 53 years old and lives with her husband and six children. I knew Annette as a patient during the seven years she underwent PD, but she was on HD when EPS was diagnosed. She was training for home HD. She had worked fulltime while bringing up her family and during the time she was on PD had successfully completed her PhD.

Annette has also since died following second surgery and reoccurrence of EPS, and I was not able to discuss the final summary with her.
Mary

Mary is a 49-year-old woman, married without children. I remembered her as a former PD patient who was on HD when EPS was diagnosed. Mary was unusual in that she had been on PD for only two and half years before transferring to HD, but she had had a transplant after being on PD for nine months. She had worked as a nurse, and referred to this during the interview. She is diabetic and had had both kidney and pancreas transplants, each of which had failed. During this time she had renal failure and diabetes Mary had always returned to work after episodes of illness. Following EPS surgery her time in hospital was relatively brief, a total of only three weeks, but to her this seemed too long. She had recovered well, although she had lost some of her sight just before the surgery and was still adjusting to her reduced vision. She was still determined to go back to work, and has subsequently done so successfully.

Cheryl

Cheryl is 44 years old and lives at home with her husband. They have four children, two of them still at home. Again, I knew Cheryl during the six years she was undergoing PD, but she was on HD when EPS was diagnosed. Prior to this she had undergone breast surgery and before the interview had just completed a course of chemotherapy. Her period in hospital was in fact relatively brief.

Sadly, Cheryl died in May 2011 due to reoccurrence of cancer.
5.3 Introduction to the themes

The overall aims of this study were:

1. To explore patients’ understanding of EPS in the context of their ‘life journey’ on dialysis.

2. To examine the meaning and impact of the condition as constructed by individual patients.

Following the methods summarised in Chapter 4, three major themes have been identified, each of which will be presented in detail, along with extracts from the interview data and my reflexive journal. Extracts are taken verbatim from recordings made during the interviews. Extracts from my reflexive journal will be included throughout in keeping with the philosophical and methodological approach adopted for this study. The three themes and their sub-categories are as follows:

1. Understanding EPS:
   - Self-interpretation
   - Not being heard
   - Knowledge and information gaps
   - Diagnosis shock and relief, and death as a possibility

2. EPS – an embodied experience:
   - Enduring
   - Bodily awareness – from others and from within
   - Struggles with eating

3. Adjustments and transitions – a journey of survival:
   - Losses
In presenting the findings the aim has been to express the process of analysis in a way that makes clear their interpretation and the decisions made regarding the themes, with my own reflections incorporated (Koch and Harrington 1998).

The themes are presented under each major heading and sub-category. Figure 3 is an illustration of the way the experience of EPS is part of the participant’s long-term condition. The process of developing the themes, based on meaningful statements, has been included in Appendix 6.
Figure 3 Representation of the Findings

Understanding EPS:
- Self Interpretation
- Not being Heard
- Knowledge and Information gaps
- Diagnosis shock and confronting the possibility of death

Living with a long-term condition

Patient

Adjustments and transitions - 'A journey of Survival':
- Losses
- Support structures and their impact
- Locating self

EPS and embodied experience:
- Enduring
- Bodily awareness from others and within
- Struggles with eating
5.4 Understanding EPS

The first major theme has four sub-categories:

- Self-interpretation;
- Not being heard;
- Knowledge and information gaps; and
- Diagnosis shock, including confronting the possibility of death.

The sub-categories are inextricably linked and are dominated by a sense of the unknown. Understanding EPS is the primary theme, and it follows from an important aspect of the experience that has featured in the literature, namely that EPS is difficult to diagnose. On the other hand its effect on the individual, which has not previously been described, can be devastating. This first theme therefore is crucial in influencing future practice, particularly the changes needed in communication with patients and the information given to them.

5.4.1 Self-interpretation

From interpretation of the interviews, the first aspect of the understanding of EPS is what can be termed “bodily awareness”. In their attempt to understand their symptoms of EPS participants become more bodily aware, and this may include experiencing intense pain, and other symptoms such as changes in bodily appearance and weight loss. As individuals who have lived with CKD for many years these participants are already quite bodily aware and interpret their symptoms within the limits of their knowledge and understanding of their illness.

Being bodily aware has been described as “body listening” and is a feature of the self-management of long term condition (Price 1993). Price (1993) adds that body listening is not merely about symptoms, however, and the body is experienced as a whole. It includes “body intelligence”, meaning that the body is also the knower and interpreter. The individual screens and evaluates symptoms to align them with what he already knows. Frustrations occur when the symptoms cannot be aligned to their
understanding of their illness (Wilde and Garvin 2007). In CKD, the recognition of patterns of symptoms often becomes focused on the technology of the dialysis and the clinical parameters of blood results, for instance anaemia. When faced with the symptoms of EPS the participants have had no previous knowledge of the signs of EPS and initially associate these with their dialysis and earlier illness. This is described as self-interpretation.

Not knowing the symptoms of EPS is a feature of lack of information and understanding, and participants try to interpret and piece together for themselves what might be causing the symptoms. There were in fact many examples that emerged during the interviews of how participants had themselves attempted to interpret the symptoms of EPS. Since symptoms tended to be gastrointestinal they did not raise any immediate alarm about the possibility of EPS. It was therefore common for participants to relate the symptoms to eating, or to their dialysis therapy or some other medical condition they were familiar with. All the participants referred to these early symptoms and how they had familiar with.

The following examples demonstrate how each participant described their symptoms. Some related it to something they had eaten:

Beryl:  I mean I... sometimes I was being sick every day, but it’d be like, ‘Oh, it’s because of what I’ve eaten’. ‘I shouldn’t eat that cheese any more or I shouldn’t eat [such and such a thing]’.

Annette: It started accelerating rapidly, it had started as four or five times a year, and 2008 it started sort of every month. And I thought ‘Oh, I don’t know what it is, it might be something I’m eating, or this and that’, and tried to console myself with different things, different, you know, reasons.

Nicola: It was so severe at the time, but then it would go, and I’d be able to lie back down and go to sleep. And I thought maybe it was just something to do with the settle... the settling of the new kidney, or... And then that went on, I suppose, right through until about April this year, just off and on, the pain. And then April this year I noticed a change whereby it seemed to be... I thought I was getting allergic to bread, because it felt as though every time I ate bread I
was getting terrible pains in my tummy. And I was in France, and I was eating a lot of baguettes.

Others related it to their dialysis:

Cheryl: I didn’t realise what was going on. Erm... My appetite wasn’t very good. Sometimes I had constipation, sometimes I had the runs. Erm... Just felt weak, no energy, things... and then it just come on gradually. Then sometimes I would think, 'Oh, it's gone away now, I'm all right’....I ended up saying, 'Oh, it's the dialysis that's doing it'....Yeah. I used to think they're dehydrating me....And making me feel sick, because it does. If they take too much fluid off you feel sick, you are sick sometimes.

Mary: I started vomiting, just occasionally really, not... not every night or every day, just at odd times. I never thought anything of it, I thought I just had an upset tummy and I would say probably February, then it was every day, if not once a day, maybe twice, three times a day, green bile. And I started that... noticing that my weight was dropping quite a lot. My blood pressure was low, and I was having problems dialysing as well, because I was dehydrated and... It was just getting worse and worse. I was still working, and just stopped feeling 100% I mean up to that point I was hoping that I'd sort it myself, or it'll sort itself out.

This next excerpt is from Michael and is similar to the way the others described the symptoms, starting with different gastrointestinal symptoms that at the time did not really mean very much. As part of the interview process they were able to reflect back to when these symptoms had started. I did not ask them specifically to list the symptoms – this was their own way of understanding when the early signs of EPS were becoming recognised as important.

Michael: When I look back, I were... Everything I’d eaten, I’d get really bad heartburn. And then I actually went to the doctor... I went to the doctor. Well actually when I did go on to haemodialysis they did tell me that you could suffer from a bit of a bowel disorder, you know, like constipation. They said sometimes you might have diarrhoea.
For some participants the symptoms came and went, while for others the symptoms gradually became worse, but they had not ascribed any meaning to them at the time.

In the case of Cheryl it was more complicated because she had recently had breast cancer. She went on to describe other symptoms such as feeling full and becoming constipated, which she attributed to the dialysis and the transition from PD to HD.

These examples demonstrate how the participants had tried to locate the problem themselves. It is not clear if participants would have reported symptoms at an earlier stage if they had been given more information about what to look out for. Moreover, being armed with the information might have alleviated some of the uncertainty and fear the condition was causing them.

Reflexive diary insert

When I initially started the process of interpretation I was struck by the common experience shared by all the participants in the symptoms they listed and described. They were not always reported, as they seemed minor and unimportant, or they related them to their dialysis. During the second interviews I realised that I had to revisit this topic and wondered what information ought to be given to patients when switching from PD to HD. I asked whether written information about the symptoms would have been useful, and they all agreed that at least some information would have been a help.

The self-interpretation described encompasses the aspects of the participant’s experience of how they demonstrate bodily awareness. This is part of the way they have become experts in their long term condition and have developed skills in its management. It also highlights how they appraise the symptoms, deciding what is relevant and when it needs to be reported. The lack of knowledge of the signs and symptoms of EPS meant that they did not appreciate the need to report them, although they attempted to interpret symptoms and determine a cause. It has to be recognised that these early signs, mainly gastrointestinal, are a familiar feature of dialysis patients. They can be subtle and may therefore not be regarded as important
(Cano et al 2007). Some participants had not reported these symptoms initially, but as EPS progressed they finally decided to mention them to their renal doctors or nurses. Earlier recognition and reporting might however have helped their subsequent management and could well have produced a better outcome, not only clinically but also psychologically.

5.4.2 Not being heard

Once patients realised that their symptoms were worsening, and they were not able to attribute them to anything that they recognised, they began to ask for help. During the first few interviews participants commented that they were “not being heard”, and used statements such as “I can’t keep on suffering”. A common aspect was that participants all felt “let down”, “ignored” or “frustrated” as they struggled with worsening symptoms, but without proper answers or explanations being provided by the HCPs responsible for their care. All the participants were conscious of the point at which they thought the symptoms had developed and how they had eventually sought help in trying to understand what was taking place. Some had endured many months of pain and suffering and it was clear from the onset of symptoms that a progressive deterioration in their condition was taking place. The stage at which they asked for advice varied, but as the seriousness of the condition became apparent they began to involve HCPs.

In the case of Beryl, for example, she describes a long period when she was in immense pain and suffering. Her husband was an expert in homeopathic medicine, and after getting nowhere with conventional medical support she tried a number of her husband’s homeopathic remedies in an attempt to reduce her pain.

During the interview Beryl referred to the pain, and of “not being heard” when she talked about returning to her renal unit following surgery. She was shocked when the staff were apparently surprised by her return:

Participant (P): Yeah. I get quite surprised when people say things to me, you know, like ‘We didn’t think you were coming back’ and stuff. And lots of people had said that.
Interviewer (I): What did it make you think when they said it? What did you feel?

P: I was a bit taken aback because nobody said anything at the time. You know, they didn’t... they didn’t even register that I was in pain really, at the time. Because they couldn’t do anything about it – nobody could do anything. And I used to feel quite upset because I was rolling around in pain and crying and screaming and they would be over the other side of the ward telling jokes and things, you know?

This above scenario took place when Beryl was undergoing HD, and she knew that the pain would usually start within two hours of the dialysis. She talked about asking for reduced hours and more frequent dialysis to try and help. This above quote has two opposing aspects, firstly that staff displayed shock that she had survived, which seems to indicate that they knew how ill she must have been. Secondly, she had been in immense pain and suffering – but she felt unheard. She felt that because no one was able to offer a reason for the pain she was in, it was ignored:

P: But for me I did feel that, like you have said, that nobody knew what was going on.

I: You were kind of being ignored, really. And...

P: It felt like everybody was like saying, ‘Well, it’s not my responsibility, it’s his responsibility or it’s her responsibility’, you know? And nobody was bothering.

Reflexive diary insert

During this example I noticed the use of the word “ignored” and realised that I had myself introduced this concept. As part of the role of interviewer I was aware of how I might be influencing the interview. On hearing the word “ignored”, she did not reject it but went on to refer to the HCPs shifting the responsibility. It may well be she was not in fact being ignored, but the HCP’s just did not recognise the symptoms – and this felt like being ignored.
For Beryl, pain became the dominant feature of her world. Beryl clearly knew when the pain was going to become a problem, and had ways of trying to alleviate it. She was not getting the answers she needed and being able to obtain relief for her pain:

*One of the worst pains I’ve ever had, screaming the place down and no pain killers were working. It was… It felt like somebody was, um… had a vice in my stomach and was tightening it, you know?*

In the case of something unbearable we look for ways of describing it that attempt to capture its severity. Language, however, as Gadamer (1975) believed, is not just a matter of signs and words, but it can express “being”. Language and understanding are thus inseparable (Linge 1977, Hans 1978).

Beryl’s recollection of pain seemed to switch time-frames when she was describing being at home and doing her best to protect her family her suffering:

*But I used to go down… I’ve got a room of my own down the end, which I used to do my dialysis in. And I used to shut the door and shut as many doors as I could between me and them, because they couldn’t cope with it either.*

By shutting the doors she was trying not only to prevent her family hearing, but also to shut away the pain; the expression is again in the “finitude” of that experience. Where it occurred is how it relates spatially, as she remembers the doors as part of the environment, and I therefore assume she was at home and still on PD. Her husband, who later joined the interview, emphasised the frustration and anger he himself had begun to feel:

*But nobody could say what it was and even if it was a blockage she shouldn’t be getting this much pain, or a partial blockage. So I was just getting annoyed and frustrated, but I was also watching my wife fade away in front of us. And we went to see the doctor and for a big meeting and said ‘Look, what can be done?’ and he said ‘Well, do you want me to talk to… there are two possible consultants that can do the surgery’.*

Her husband describes the anger and frustration he felt when nobody seemed to be listening to him, and witnessing his wife getting worse left him feeling helpless and out
of control. This was compounded by his own medical knowledge, as he tried to look for
answers and ways of alleviating her suffering. However, in the above quotation Beryl’s
husband comments on two consultants who could do the surgery, giving the
impression that HCPs did actually know what was causing the symptoms. It can only be
assumed they had not arrived at a diagnosis of EPS. For Beryl, feeling alone continued
even after the surgery. There was still a strong sense that no one cared:

*I haven’t seen a doctor since I came back. It makes me think I should be making
arrangements to go back to another unit somewhere else, where someone will
be bothered. But I don’t have the experience to choose. I mean, is it better the
devil you know?*

Losing trust in the HCPs is a major factor in compounding the sense that one is alone
and that nobody is listening. Even after what Beryl has been through she still feels
isolated.

In Barbara’s case she provided a lengthy description of how she had had trouble for
many years with her bowels, which were always “blocked” after a general anaesthetic.
The example below was from the second interview, when she had been discussing her
visit to the surgeon who had provided the EPS diagnosis. I asked whether she was
relieved at that point:

*Oh God, yeah because I had been saying to the doctor for a year, surely there’s
something somebody can do, I says, because I can’t keep suffering like this, it
was horrendous. The pain I was getting... I was just so ill. The vomiting, I’d keep
vomiting. My bowels would just pack up, they wouldn’t work at all for two or
three weeks. And I thought, you know, my husband he was saying, you know, it
was hard for him to see me in this way, you know, it was hard. Because he could
see me suffering and there was nothing he could do. I mean he would empty the
bowls, because the bowls would be full of faeces. And you know, he’d have to, I
mean it’s a good job that he was there because he would pass me the bowls
and I would be vomiting, and he would take it away, I would be vomiting again,
and it was just all coming up. I couldn’t eat, because it wouldn’t come out.*
At the beginning of the interview there was desperation in Barbara’s voice, and she had clearly reached crisis point. As a researcher I was compelled to step back and try to come to terms with this. It is of course related to the problem of identifying EPS, but the entire experience was highly traumatic for the participants. It had driven them to the point of despair.

In the case of one participant, Annette, my situation was particularly difficult, as I had been involved in her care when she presented to my own unit. My relationship with her had therefore been clinical before the first interview. She expressed a feeling of anger and frustration, and even blamed herself. I was not surprised as I listened to her, and it really challenged my own pre-understanding:

*But I mean initially I was quite angry, and I was quite frustrated and angry that people didn’t tell me. Professionals didn’t tell me, didn’t give me a choice, didn’t do this, do... And I’ve heard other people saying ‘Oh well, you have got to have a choice, you know, people... They do give you a choice and, you know...’*. And I said ‘Well, why... why wasn’t I given a choice then?’, you know, it’s just like that, isn’t it?

*When I found out, you see, and this is why I blame myself. I went on to the internet and all the symptoms were there, and everything... all the details, and I said ‘Why the hell didn’t I look into it, you know, before?’*

*I was so trusting, you know, because I trust the professionals, trust the doctors and nurses, and you do that if you are a patient.*

Annette had started to blame herself because she felt so let down by HCPs. I have included here an excerpt from my reflexive journal written immediately after the interview. This demonstrates the personal dimension to this research and how I needed to try to remain focused on the text for its critical interpretation. My reflexive account in fact provides an illustration of my own prejudice:
Reflexive diary insert

When I conducted the interview Annette had a very different view than my perception of what had occurred when she was diagnosed. I too felt angry at times listening to her perception but it really made me think hard. I did not feel I could question her, even though I remembered well the consultation I had with her lasting over an hour explaining everything. It seems that she regarded the surgeon as the “saviour”, as he gave the diagnosis and it was he who had the opportunity to alleviate the symptoms. However, we are always told that we should follow patients up and question how much they understand, and with hindsight I know I felt quite drained and wanted a doctor to come along and deal with the situation for me. I honestly don’t know if I did this. I remember sharing the anger she felt, even though I had acted promptly when I was given her symptoms. I know that at the time I did have a discussion with a consultant to try to rationalise what had occurred. However this is part of the reason I embarked on this study. Being close to patients who develop EPS is like a constant guilt as to whether something could have been done differently. On reflection, as the interview went on I appreciated that this is an example of what happens to patients, and perhaps surgery is the only time it sinks in. I also realised that I might have influenced the consultation as I myself was feeling anxious. I don’t know now if I did say she had EPS, and in essence it doesn’t matter, as she recollects symptoms over long periods of time and the countless occasions when she asked for help. I also know that she did not always attend her clinic appointments when she was on PD during the time she was very well, and I was glad during the interview that she did acknowledge how independent she had been at the time.

Not being heard leads to a loss of trust in the HCPs and inevitably leads to a feeling of being neglected. As Mary describes:

*Cos I really feel like from the... the sort of Christmas time, right through to March, I was on my own, with no suggestion of what it could be, and I was just plodding on and sort of struggling to keep my fluids up, and erm... try and keep healthy. If I had some idea that it could have been that I could have seeked some help.*
Mary did report her symptoms to the renal specialists, the community nurse and her own GP, but does not seem to have achieved a satisfactory outcome. Eventually she was referred for an endoscopy, which would not have revealed anything in terms of EPS. As a nurse herself, however, she felt it might be appropriate on account of the vomiting she had been suffering. During the interview she described this in greater detail as part of her own interpretation, and this will arise later under the theme of embodiment. It also highlights the significance of patients’ own level of knowledge and expertise in their attempts to overcome their problems, at times putting up with more than they need to.

Cheryl emphasises how the lack of trust even made her doubt herself:

*And then about two weeks later I started again, feeling gradually worse, feeling sick, but I wasn’t sure. They reckoned it was down to anxiety, stress, because I’d had the diagnosis of breast cancer and not told the rest of the family. There was only a few of us knew. Erm... So I started thinking that as well.*

Cheryl’s case was complicated by the fact that she had already undergone surgery for breast cancer. She was being told that her symptoms were caused by “anxiety”, and since at the time she still had trust in the HCPs she almost believed it. This again emphasises the dominant nature of the HCP–patient relationship, involving both uncertainty and power, by giving a patient a virtually psychosomatic explanation for her vomiting.

A sense of “not being heard” or “ignored” could also occur following surgery, particularly when participants returned to their own hospital and little or no follow-up was provided. It was particularly poignant to listen to some of the accounts, and at times made me almost speechless, not only because of the clear clinical picture I was being given but also the emotional turmoil created. It did not seem to matter how long the participants felt the symptoms had persisted, the sense of not knowing and being ignored was very evident. This had obviously caused frustration and anger. In essence these participants were used to understanding their bodies and had come to terms with what to them was a “normal” state of being on dialysis, but EPS posed a different challenge because it was outside any expectation they may have held. There were
times when participants indicated that EPS might have been mentioned but was not taken seriously by themselves or the HCP’s. The participants often had to reach the point of desperation before anything seemed to be done.

Reflexive diary insert

Initially I gave the title “abandonment” to this first sub-category. As I had interpreted it as such, I also presented the initial findings at a National Conference where I had been invited to speak. I was approached by individuals who felt it was very powerful and resonated with their experience. One individual in particular, although a nurse, had a brother who had just been diagnosed with EPS. She felt strongly that his doctors had been ignoring both her and her brother’s own concerns about his symptoms. I reflected on the use of the word “abandonment” and realised that this was more in line my own feelings, and as such I had tried to put my own views into the interpretation; I felt they had been abandoned. Reading and listening to the text again a more appropriate interpretation was that they were “not been heard”.

5.4.3 Knowledge and information gaps

There were many times during the study when information and knowledge were severely lacking for these participants, and this had created uncertainty. The uncertainty associated with the experience of EPS arises from not knowing or understanding its symptoms, uncertainty about the surgery required and assuming they survive the surgery, the nature of the outcome. Interestingly, the uncertainty of the participants was reflected in their interaction with the HCPs caring for them. Part of the reason for undertaking this study was related to the issue of clinical uncertainty in the early stages of EPS. The perceptions of these participants confirm that this is indeed a major issue.

Many examples of the suffering the participants underwent have already been presented, and also how they themselves tried to rationalise the symptoms in the light
of their earlier experiences and understanding. Few had heard of EPS and how it might be manifested. It was something totally new, and was not immediately connected to their CKD or to the dialysis they had been undergoing. The participants’ experience of EPS could sometimes be compared to when they had first developed CKD. The information and knowledge gaps refer both to the participants and also to the HCPs.

The perceptions of the participants were that the HCPs did not know enough about EPS, and this was frequently commented upon. They often made reference to the length of time they had been on PD, and this will be revisited later in the findings when the theme of losses is discussed.

According to Cheryl:

I don’t think they know enough about it. They’re not confident in saying anything, because their field is haemodialysis, so really they probably don’t know much about the peritoneal dialysis. So it’s like... it’s not their field.

Knowing that something could have been done about it before it got that bad. But you listen to other people, don’t you? And you do think, oh, it’s anxiety, it’s this, it’s that, when really I think if there was a bit more information about it that you’d be a bit more aware. But it’s hard when you’re on dialysis as well, because you don’t know that if it’s the dialysis causing it.

Erm... And when I look back now I think how long did I have a bowel problem for, without really realising it was anything to do with the EPS...Whereas... There’s nothing wrong with the nursing or anything at the hospital, but maybe it’s not in their heads, 'Oh, this person’s been... was on peritoneal dialysis for six and a half years, something’s not right'.

Beryl provided similar comments:

I: Do you think if they had said something to you at the time, ‘Look, we know what this is’, do you think it would have made any difference at all?

P: I don’t think they knew what it was.
I: _Do you not?_

P: _No. I don’t think they... they had any idea about it. It seems as if, you know, because of [hospital M] being the centre for it that everybody was geared up there, but it felt like we were little country cousins who didn’t know anything about it here._

She also commented on a question I had included in the written interpretation:

P: _I think it’s like you... you say the question, 'Do you think it would have been more helpful to know the risks of EPS ?..... I think it would have been better to know something than to know nothing, because you... you know I... you know, like the journey in to do dialysis was awful, because I knew what was coming. And I would rather have known than not._

It is interesting that participants acknowledge that HCPs lacked knowledge, but this did not justify the pain and suffering they had endured and which rendered them powerless. It highlights that HCPs were adding to the level of uncertainty by appearing to not acknowledge what was happening.

All the participants were very much aware of the importance of information and knowledge. As Barbara states:

_No, they didn’t know anything, did they? But they need to. They need to know everything now, because it’s people’s lives at stake. It’s not just, you know, it’s not just something that they can cure, because I’ve lost part of my bowels as well._

Before the second interview Mary had even made a note about how she considered the renal staff should be trained:

_I mentioned it to her, and she didn’t think it was a renal problem, and just sort of said, well we’ll see how you get on.....And I just put a little footnote there, about home sisters maybe being aware of EPS, 'cos I don't think... You know, of symptoms, and maybe catch it before it... it got to the, you know, three months..._
Simon, who had lived with CKD for 30 years, made this very clear:

_I didn’t know that it was related to the peritoneal dialysis, because nobody told me really. It was only when I asked more about it that I found out that it was..._

Many participants had investigated EPS once they knew what it was called, searching the internet and asking other patients. These participants had more information, but they had also begun to realise just how ill they had become. Three participants made reference to receiving some information about EPS, but at the time they did not think about it very seriously as it really had no meaning to them. In the case of Barbara, for example, she said the doctors had mentioned it, but in the interview this came across as follows:

_The doctor said something about... something on the lines, probably about seven years ago, 'We can’t keep you on CAPD for that amount of time because there’s a thing called peritoneal sclerosis. Which means basically...' Well, they didn’t explain it, they just said it’s a nasty disease and if you get it, you know, we just want to be careful. Well at that stage the dialysis was going really well, the CAPD, so I didn’t want to change on to haemodialysis, because I never wanted haemodialysis, so I didn’t really take much notice._

Barbara is clear that no real explanation was given, and she knew that she had wanted to stay on PD as a therapy as it was working well, and at the time it was all she knew about. Saying “they didn’t explain it” is the relevant comment here, as the HCPs clearly knew about EPS, but this emphasises the difficulty resulting from how it is communicated. Since CAPD had been going well, Cheryl with hindsight rethought the missed opportunities arising from her diagnosis not being picked up sooner:

_P: Erm... But in hindsight now, I had a chance to... for the consultant to do a laparoscopy, but it was going to be Christmas Eve. No, yeah, near Christmas, wasn’t it?_

_I: Yeah._

_P: And I just wanted to get home from hospital. If I had had a laparoscopy he might have found out that...I had EPS?_
At this time Cheryl had just switched to HD and wanted to become settled on it. She had started to feel better and so more surgery merely meant more time in hospital. Again, the procedures or interventions by HCPs must be balanced against patients’ own choices.

Sometimes the participants hinted that they suspected that other professionals knew the answer but they were not saying anything. As Simon points out:

And then I went on to haemo and I started getting stomach pain whilst I was on haemodialysis at the unit. And I mentioned it to the doctor at... on the dialysis unit and I went in for a scan, and there was nothing said. I think there was some signs of sort of a indication that it might be there, but there was nothing said to me at the time.

This is very similar to Annette’s experience:

You might as well, you know, try and find out what’s happening. Because he... he wrote all the symptoms and it was quite a lengthy sort of... he was trying to diagnose what it was, and I think he did come to the conclusion that it was EPS. But he said, ‘I knew, but I didn’t want to say anything until the big boss saw you’.

This apparent reluctance of HCPs to discuss their suspicions seems somewhat short-sighted, particularly when patients are describing their symptoms. It seems that the issues surrounding EPS create reluctance on the part of HCPs to be open and honest. During the second interviews I discussed this at length with the participants, in particular that HCPs are sometimes disempowered by the lack of effective diagnostic testing. In addition, a more holistic view of the illness experience should enable HCP’s to view symptoms in their entirety, not just biomedically.
Reflexive diary Insert

In the light of my own experience and prejudices I can relate to this. I have always wondered if as HCPs we are right to have our own suspicions but not to share them with our patients. During discussion at meetings about when and how we should discuss EPS the debate, especially from PD colleagues, is that we must be realistic. The risks of cardiovascular disease, for example, far outweigh the risks of EPS. Unlike cardiovascular disease, where certainty arises from a wealth of evidence, there is uncertainty about EPS as a “disease” that cannot be pigeonholed into a definitive or text-book scenario. However, this is a totally biomedical view and does not take into account the emotional and psychological wellbeing of the individual experiencing the symptoms. The participants’ accounts of their experiences are not just about their physical symptoms, they also describe the emotions and suffering they have had to endure. The information, support and reassurance they have been looking for from the HCPs around them often appears to be lacking.

There were times during the interviews that we touched on the uncertainties of the clinical and biomedical aspects of EPS. This was challenging in many ways, particularly when the length of time on PD therapy was discussed. This will be referred to later in the findings. I tried to provide answers to the clinical questions from the evidence base and attempted to avoid allowing my own opinions to intrude. However, some participants asked specific questions about their own experiences and what they had read or heard. I am not sure that all of these issues are currently resolvable in clinical practice, but what is not in doubt for these participants is how lonely and uncertain the onset of EPS can be. The thirst for knowledge became more evident in the second interviews, with participants looking for answers, in particular about the causes of EPS.
5.4.4 Diagnosis shock, and confronting the possibility of death

The diagnosis of EPS is beyond doubt a highly significant event. The need to have access to someone able to listen was very evident, as was the subsequent relief at having an explanation of the symptoms they had been experiencing. It was also sometimes tinged with shock. Meeting the surgeon was a new voyage, a new relationship built on trust, and even hero-worship. There was immediate faith in the abilities of the surgeon, not only to save them from inevitable death but more immediately to relieve their suffering.

Recounting the actual consultation was a common element; the risk of death and the impending surgery meant participants could now begin to appreciate the cause of their symptoms. The realisation of what EPS meant and the desperation they felt paved the way for the battle ahead. Participants perceived there was no choice or decision to be made, but an acceptance of what needed to be done. Being in possession of a name for their symptoms enabled them to seek out more information from a number of sources. It was also common for participants to refer to their original diagnosis of renal failure and to make comparisons. Both had disrupted their lives, but EPS was not something which allowed them to see very far into the future. The diagnosis enabled them to piece the jigsaw together, giving them chance to reflect and in a sense to gain meaning. This led to the more existential effects of meaning, reviewing their past experiences, considering the meaning of life and how as individuals they could face the future.

For some of the participants the relief of being given a definitive diagnosis no doubt alleviated some of the uncertainty, but the focus of the uncertainty then shifted to the risks and outcomes that were being described. The consultation with the surgeon was for the most part perceived in a very positive way and how information was communicated seemed to have an impact on them as individuals. It was common for participants to use the expression of relief in the interview, as demonstrated by Annette:

\[\text{P: Yeah, I was relieved because at least I knew what was wrong with me, yeah, because before that I didn’t.. I just thought it might be something else.}\]
Annette goes on to describe her fear allied with a feeling of hope once she had met the surgeon, especially when thinking of her youngest child:

This is it, this is why when I saw the surgeon and he... you know, he diagnosed. And, you know, this is why I felt the consultation and I thought, oh god, right, you know, there might be a chance now. I might still live to see her grow up, you see. And that was... that was the main thing revolving in my head at the time. I wasn’t... you know, she’s quite attached to me, you know she’s a little girl.

The hope is situated in her now realising that she may not die – there is a chance that she may survive. Annette was probably the angriest of the participants, and had reached the point of despair. The significance of the diagnosis was that it changed her attitude towards dying, and still being there for her youngest child was something she could now look upon as a possibility.

For Simon there were two different ways he was told he had EPS, the first example being the doctor from his local renal unit:

And anyway the first time that I said anything to the doctor on the unit about, you know, my bloated stomach and the pain I was getting and my loss of appetite, which was all the things that I’d noticed. He said ‘Yeah, you know, you’re going to have to have an operation’, or actually said ‘Well, we don’t really think that you would have an operation, because with the condition of your heart’. Now there was no alternative given, so presumably it just meant that I would fade away, you know?

The second example was as follows:

P: And then I went into outpatients to see one of the surgeons. And he said ‘Well, look, you know, you’re really going to have to have surgery, because there’s no alternative’. And I think this was in the February and I said to him ‘Well, you know, if I don’t have the surgery my daughter’s having a baby in the end of March’, it might be April, I’m terrible with dates.

I: It doesn’t matter.
P: Anyway, I said ‘Will I see the baby?’ you know? And he went ‘Mm. You know, I don’t really think so’, and that brought it home to me how serious it was.

In the second scenario the impact seemed more real than the first, even though Simon presumed he would be just left to fade away. Further into the interview he says he presumed he “was for palliative care”, using those exact words. He also made reference to his first encounter with a doctor:

Yeah, because the doctor had just sort of said that in passing, you know what I mean? And I thought ‘Nah!’, because you don’t really, do you? You’re in denial, you know what I mean?

His initial medical encounter left him with the feeling that he was just going to be left to die, and it was not an encounter that held particular significance as it was just “in passing”. The formality and environment of giving bad news can affect how seriously the information is accepted. Simon also uses the word denial, a way of coping with the information that was given to him in a passive way. The second encounter in a more formal setting was still traumatic but had greater meaning – he realised that without an operation he would die. He was given a very poor prognosis of only a 20% chance of success, but he accepted it calmly. These excerpts from the interviews demonstrate that Simon is a person who knows himself well and how he is able to compare the different challenges he has faced, and his determination is clear. It helps to understand his view – that he feels lucky to be alive.

P: You see, the thing is that I’ve always been a worrier, right? I’ve always when I’ve had operations of any kind, even minor operations I’ve always been extremely worried. Even if they’ve said ‘Well it’s a minor operation’. I had an operation on my knee, it scared me to death. This one I was more calm about strangely, because I thought it’s a straight battle, you know what I mean?

It was either, have it done or die. I mean that’s an easy op... an easy thing isn’t it really? Not so easy on the missus like, but you know?

This was like it’s a straight fight and I’ll either win it, or I don’t and that’s it. And not really expecting to win it, but knowing that, you know, I’m going to give it my best.
Simon describes it as a straight fight, an acceptance of what lay ahead. Again there is the view that he has no choice, because the only other option is to accept death without a fight. Being given a chance, a glimmer of hope reconciles Simon to facing it head on – and perhaps even winning:

P: You see I’m a bit sort of... I think I’m a bit sort of bi-polar in that way, I’m very positive when I’ve got... when I’m up against it, but when things are going well I can be very negative looking for things that are going wrong, you know?

Well, I mean my worst thing is being told that I might have renal failure. I remember in 1984 being told that I might have renal failure. Once they’d actually told me I was the... I’d got renal failure and I was going to go on dialysis, then I thought 'Well, okay, I’m going to be the best dialysis patient... ever want to be. Yeah. I’m going to do it. I’m going to do it at home and I’m going to work and I’m not going to alter my life. I’m going to stay healthy and I’m going to do it, and I’m going to be... you won’t even know, you’ll think I’m the best, wonderfullest, you know? And that was fine.

Simon again refers back to his original diagnosis, as did many of the participants, but his description of when he is well and how he worries relates more to “chronic uncertainty”. A sense of not knowing, and anxiety of what might be, is a negative emotion, but this was not the case with EPS, and once he realised its significance it became a straight battle.

The inevitability of what lies ahead has been a common thread, and for me personally I hadn’t realised just how desperate these participants had felt. It acknowledges the fact that, when faced with such suffering, pain and desperation, the very chance of survival as a human being is something to cling on to.

For Barbara the desperation once she had met the surgeon meant that she wanted to prepare herself physically and psychologically and did not want to wait for the operation:

P: I don’t think I would have survived six months, another six months, if I hadn’t had it done. So really I hadn’t got a choice, I’d got to have it done. There were no ifs or buts, it had got to be done....I was ramming everything down me to
keep me going and drinking those shakes to build me up because I knew how big the operation was.

Barbara even contacted the hospital to try to bring the operation forward. She felt she just wanted it done as soon as possible, as her life was hanging by a thread.

The desperation and relief could be heard in the voices of many participants during the interviews. The perception of having no choice emphasises the amount of suffering they had endured and their need to survive, as they felt death could be close at hand.

The consultation with the surgeon provided them with relief, despite receiving details on the probability of death and the complications that could occur. It is during this consultation that the participants sensed that a degree of trust was restored within the healthcare relationship.

In the process of giving the diagnosis some surgeons described death and the possibility of it becoming a reality. The sentiments felt for the surgeon were strongly reflected in the interviews. This may be partly because they found themselves in a desperate situation, but even so the manner and communication used, not just by one surgeon but the whole team, was regularly mentioned. Participants often described the interpersonal skills and individualistic approach used, and terms such as “hero” were used. A trusting relationship helps to build confidence, and the comments made by Mary and Annette exemplify how strongly this was felt:

Mary: I had every confidence. Yes. And I did... and I didn’t even worry that he wouldn’t manage it, for some reason, and that he would do his best, and that’s all that I really wanted from him, and that’s what he gave me, he delivered it well. He was my hero, he was.

Annette: So there I’m in a state of shock and I keep on thinking I’m going to die anyway. So when the surgeon comes and he like... he’s your saviour, isn’t he? He’s going to save your life, so you are going to feel that consolation. This is it you see.

Actually, he’s the only person I think I admire now [laughs]. After all I have been through. Because... because he’s just got and saved your life, that’s why you
love him. Yeah. And my son said I want to meet him, because I want... I want to meet the person who is saving my mum’s life. So he went in and he shook hands and, you know, he was... you know, I said ‘He’s a... my son’s a big fan of yours now’ [laughs again].

All the participants made reference to the trust they had, which could be attributed to them feeling “saved” from inevitable death. Consequently the praise they had for the surgeon was emphasised over and over by many of the participants.

Possibly because they felt this degree of trust, death was an aspect of the experience that participants were prepared to discuss. The fear of death was not only related to EPS but seemed to be something they had been aware of throughout their long term condition. This was often demonstrated when they indicated that they had always thought dialysis would inevitably be the eventual cause of their death. Surviving EPS almost took this feeling away, as to them it was by far the riskiest and most serious illness they had had to survive. Death as a possibility was part of the hermeneutical view of “being” and the authentic self described by Heidegger (Heidegger 1927:1962, Guillickson 1993). Preparing for death was part of the process, as Barbara describes:

P: Yeah, we had an extra special Christmas. Because I didn’t know whether I would be around for any more. And it was a difficult time.

I: That’s OK. It’s bringing it all back.

P [crying]: I remember going down to theatre with my husband and my two sons and my daughter-in-law. They were all crying because they didn’t think I would make it. And it was just...

Barbara was lost for words and became very emotional. We remained silent for a few moments. She then described how she had wakened up after surgery and felt relieved. She described the fear she had and the fact that other patients had died. Barbara was in hospital for so long that she witnessed a number of others dying. This was both a reminder of her own mortality, but also gave her a sense of “feeling lucky” to have survived so far:
P: Scared. Absolutely scared stiff. Because I knew he’d lost patients, he’d told me. And he said that the EPS don’t always work the first time that they operate. And while I was in there one of the lads who had the operation, he passed away. And I felt awful because I’d been talking to him... I mean I had because he’d had the same operation, when he came in to have the operation I’d just had mine, the first one, and I says to him, ‘Oh don’t worry about it, it is straightforward.’

Yeah, he died in the side ward. And two other people who I knew who had the same operation and had a stoma and everything the same, he passed away after I’d left hospital. He went down to have a bowel transplant down somewhere and he passed away with an infection. And then there was another lady who had it done and she passed away as well.

For Barbara it raised a range of emotions from feeling guilty and then feeling lucky.

In the case of Simon, he was prepared for death, but that did not mean he had given in to the idea that he was going to die:

P: Basically, I just said to my wife that I wasn’t going to be coming out of hospital, ‘Don’t expect me out of hospital, because...’. And I got everything sorted...Yeah, I thought what I’ll do is I’ll... if I can get through the operation and I’ll just concentrate on getting myself better and work at it, you know? And, because I know everything is sorted out and my wife is expecting me to come home, so if I do make it it’s a bonus and every day that I’m home is a bonus, you know? So that’s how I...

I: Was that hard at the time? Is that a conversation you’ve never had before, I presume?

P: Well, I wished that... No. It’s not... Yeah, it wasn’t a conversation that I had with my wife, if that’s... Do you mean with my wife?

I: Yeah.

P: It was more of an understanding that I built up, because initially when I mentioned about it I sort of said, ‘Well, I’ve got this...’. Because I’ve had a history of medical problems and this is just like another one, I’ve got this. And
then I sort of said, ‘Well, it’s a bit more serious and perhaps it’s a little bit life-threatening’. And then it’s majorly... so you know what I mean?

As a way of protecting his wife, and possibly himself, he made preparations in advance. As he had had renal failure for over 30 years he knew his wife had seen him go into hospital before. Late in the interview we did discuss death and whether it had ever been something he had thought about previously:

P: There were times when I’ve been extremely scared that I was going to die.

I: Okay.

P: This was more of a ‘Yes, I may die. Okay’.

I: Okay. It was different?

P: Yeah. ‘Or I may not’. The thing is you realise that if you’re going to die, really you’re not going to know anything about it, are you?....

So death is something that was present but not overriding; later in the findings appraisal and adaptation will be described in relation to these feelings. For these participants the main cause of their fear and anxiety was about the people who would be left behind.

Cheryl became distressed during the interview when she talked about the uncertainty of dying, but also described how she comes to terms with that uncertainty. Again, her emotion was directed towards her family and children. She described her feelings about dying, how she dealt with these and how they had actually been integrated into her life. The meaning of EPS was now more real to her than when she had first become ill with renal failure, but even then her primary concern was the impact it might have on her family:

I: Okay. What was the scariest bit through all this?

P: Erm... Whether the operation was going to go well.

I: Okay.

P: Erm... And because... you’re making me cry.
I: I'm sorry.

P [crying]: You know what you're putting everybody else through.

I: I know.

P [crying]: Whereas last time, because I collapsed and I was out of it.

I: You weren't aware.

P [crying]: It was easier on me. But just so hard for the family to be all waiting at home. I know they've got to tell you the worst, and it can go one way or the other, but they didn't know what they were going to find....until they opened me up, did they? I think that. No. When I'm well I think oh right, I'm alright, I'll be okay. Erm... When you're ill, and you're being sick, sometimes you think oh, I've had enough of this.

The words “I’ve had enough” summarise the despair felt by these participants. In the original headings I had included “desperation”, an aspect of the experience of EPS that could be heard in the voice and the words used. This has already been frequently mentioned and will again be emphasised later in the findings. At the point when Cheryl said, “You’re making me cry”, I was sitting back on her sofa. I immediately sat up straight to correct my posture; we were close together and I had not been prepared for this.

Asking difficult questions is inevitably going to stir up emotions and the fear of what lies ahead. On rereading the transcript I realised that I had raised a difficult issue when I asked what had been the ‘scariest aspect’, and my use of these words was perhaps unwise. We both agreed that the difficulties lay with those who were left behind, something I had talked about with another participant on the same subject; this was not so much the fear of death, but fear for the family. The feelings of guilt arising from the impact on the family were clear from a number of the participants.

Later in the interview Cheryl again discussed the impact of her dying on her family. It seemed that she shifted from the constant worry that death brings, to focusing with effort on how she prevented the emotion and negative thoughts from taking over her life:
P: Yeah. It’s daft, because you go through stages where you’ll think right, he [son] can learn to cook himself, he’s like 16, and put the washer on. And I think you’re at a constant thing all the time, because you worry if you’re not going to be here how are they going to cope. And then they’re like... they’re teenagers aren’t they, and the... teenagers are bloody hopeless, aren’t they? But I mean they would cope, I know they would.

I: Yeah.

P: If they’ve got... they’ve got enough people round them, and stuff like that... But it’s just... just the thought of it, isn’t it? But then people lose their parents all the time, don’t they? Not because they’re ill......Because of other things.

I: Yeah.

P: And people say that about, erm, dying, ‘Oh God, how do you cope with it?’ And I say, ‘Well nobody knows when they’re going to die. You might die tomorrow.’

I: No. Oh no.

P: And my thing is, I’ve got the dialysis, I could have a problem with that. It weakens your heart, your lungs, I could have a problem with them. It doesn’t have to be the cancer that kills me.

In the above quotation it is the cancer that Cheryl refers to, not EPS, but then she is considering a number of things that could lead to her dying. It is an existential view of life and she is trying to put her illness into a grander context when she says, “You might die tomorrow”. This is a conscious attempt to deal with thoughts that she has to cope with when facing such an enormous and potentially life-threatening illness.

Annette described many times that because nothing had been done quickly, she believed as a consequence she almost died, but that she was not frightened of dying. Once again, it was the family left behind that gave her most concern:

I: Were you frightened of dying then?
P: No, I wasn’t frightened of dying….Yeah, I thought… Yeah, I wasn’t frightened of, you know, dying, you know, as such.

I: Yes.

P: But I was frightened of… you know, because you’ve got the kids to consider and I’ve got… I’ve got a twelve-year-old and I felt so bad for her. Because I know the others are adults and they’re going to… well, I know they don’t cope and it’s… it’s really cruel to say that. Oh, they’re going to… you know, they’re going to cope without their mother.

John described the fear he had the night before his surgery and how he made preparations with his son relating to practical and financial issues:

P: Oh yeah. Yeah. I had explained it to him and said, ‘This is what I want doing. If there’s anything happens, this is what I want doing’.

I: Sort of settling your affairs.

P: And my daughter wanted… she saw these fashion things in the sale and I says, ‘Here you are, you can have them, Merry Christmas’, and it was July, no, August.

John then talked about the realisation of how ill he had become and, although he did not use the actual word, he knew that dying was something looming as he struggled with weight loss and being unable to eat:

P: Well sometimes you think is this it? You do, because how can you live on a piece of string like. Bearing in mind half the time I was just being fed intravenously.

He also described his fear the night before his surgery and, like many, the relief when he awoke the following day:

P: I was nervous as anything on the night before, and on the morning I came back, I thought that’s it, stop being stupid, you’ve gotta get it done, that’s it. So I had this totally different outlook. If you ask the wife, you’ll ask her about the day before and the day after, I was two different people.
The relief felt the day after the surgery was also described by others, relief because by surviving the operation they had come through the worst.

In summary, this first major theme has covered many aspects of the experience of EPS. Whilst presented as a theme with sub-categories I have demonstrated some of the individual meanings to that experience. The early symptoms of EPS were initially perceived as a process of self-interpretation, and then being misunderstood by HCPs created uncertainty and anxiety. The main threads of this relate to “not being heard” and having to suffer pain and other symptoms, sometimes over many months. The desperation felt was clear from the descriptions given and in their voices as participants recollected their feelings. Participants’ understanding of what had been going on was alleviated through the consultation with the surgeon, finding someone who gave them hope and whom they immediately trusted. The shock and relief was clearly expressed by the participants and they were then able to focus on a journey involving fear and death as a possibility. They constantly compared EPS and the other elements of their illness. For me this was something I had appreciated, that EPS could not be taken out of the context of their long term condition as a whole. Past experiences influence our understanding and meaning of the present and the future.

Gaps in knowledge can clearly be detected throughout, and the perception that HCP’s had little understanding of this has major implications. On the other hand a condition as rare as EPS is always going to be difficult to communicate, and I did explain to the participants the problems facing clinicians. The second interviews took place when they clearly were thirsty for knowledge, asking lots of questions and coming up with
ideas they thought might help. This gave an opportunity to share our understanding, as from their perspective they all felt they should have been given more information.

5.5 EPS – An embodied experience

This theme encompasses the existential and phenomenological views of the bodily experiences described by the participants in this study. It has three subcategories:

- Enduring
- Bodily awareness from others and within
- Struggles with eating.

Although different terms have been used in the literature such as “embodiment”, ”the lived body” and “bodily experiences”, from a phenomenological perspective they refer to the work of Merleau Ponty (1945) (Wilde 1999). The terms “body” and “self” are existential, so when presenting the findings the term “lived body” does not refer to the body as a set of organs and limbs, but as a subjective body within the lived world. The object body is one that is separated from the”lived experience” and refers to a body that is separate from the self.

Throughout the presentation of these findings these concepts will be discussed from the point of view of the participants in the study and how they reflect the phenomenological concept of embodiment and disembodiment.

Individuals with CKD often find themselves in a technological and biomedical environment in which their bodies are the focus of their illness. The lived world for them is therefore different, and the sense of body and self is already part of their experience in how they have adapted to long term condition and dialysis.

5.5.1 Enduring

Endurance has been defined by Morse and Carter (1995) as the capacity to last, to get through, and to survive an experience or an intolerable situation. Situations that have
to be endured are usually ones that the person is forced to undergo; the individual has no alternative but to endure them (Morse and Carter 1995).

For Beryl, Simon, Barbara and Michael the length of time in hospital was more than four months. In particular, Barbara and Michael had open abdominal wounds that were dressed with a special vacuum dressing to enable healing, but which also allowed the surgeons to take them back to theatre for ‘washouts’; this can occur in patients who have undergone EPS surgery and is an accepted way of managing the enormity of the damage to the bowel. Living through this experience imposes major bodily disruption. For these five participants endurance seemed a never-ending procession of operations, pain, wound washouts and infections – “tubes, and more tubes” (Beryl). Their time in hospital became a blur of reality as each day rolled into another, waiting for something positive to happen. It is also important to consider the lack of preparation they had. All the participants knew they were going to undergo major surgery, but no written information was provided. The only real information was given in the consultation with the surgeon when the opportunity arose. Two of the participants had been admitted unwell and did not have the benefit of an outpatient consultation.

This is how Beryl recollected her four months in hospital:

_I only did one day in intensive care. And then I went straight back on the ward and I had the heart attack on the ward. And they put a stent in, and shortly after that I had pneumonia, and then after that I had pleurisy. So I had twenty-six tubes going in and out of me after the surgery, so I couldn’t move and they were all coming out one by one, you know. And then when I got the pleurisy they had to put two more tubes in. I had an abscess under the diaphragm and I had an accumulation of fluid on this side, which was about... this was two litres and this was one and a half and I had those drained. And I’ve still got fluid there now, but it’s not as bad, it’s lessening._

Barbara spent six months in hospital and described the whole period as a series of events:
Well, I ended up having 20 operations. I was in for six months. I ended up having my toe removed because of the blood supply. I’d banged my toe on Boxing Day in the bedroom and it went black. What had happened was the blood supply weren’t getting to my feet properly so I had to have an operation in there to put stents in and blow the veins with a balloon. I had that done, my toe removed. He had to get in some special stuff from [America] to clean out the wound and he did that every five days. I was in theatre every five days for weeks because it just wouldn’t clear.

It is important to acknowledge that listing the events like this may be a reflection of how difficult the experience can be to describe, as the above excerpts demonstrate. There is little emotion within the words, almost a monologue describing the horrific events that had taken place.

Another excerpt from Barbara’s interview indicates what she had to endure when she became unwell after the first operation:

Well anyway, needless to say my bowels were blocked again. I weren’t going to the toilet. They give me enemas after enema, nothing would move me. And anyway the pain started again. And the pain... I was screaming with the pain and they rushed me back to theatre at midnight on the... I think it was the Friday night, I am not sure now... and I’d had... I was having a panic... I was having panic attacks because I was hyperventilating. It was just horrendous. I didn’t know what was going on and I went back to theatre and then when I woke up I had got the stoma and all my stomach was all open.

Then later:

And then I just... It was just like... It was just... I can’t explain, it was just so horrendous. The operations, one after the other, after the other. You know, every five days I’d be... they’d be... by the time I’d recovered from one operation I was back again for another one.

Barbara just could not understand it, and she just had to endure it and look for the strength to carry on. The panic for Barbara and pain she had to endure was intense; her voice during the interview echoed the desperation she felt.
Michael describes a similar experience, of going back and forth for operations:

_I used to hate it, having to go to theatre to have me wound all dressed and taped, and you know, all cleaned and whatnot. Oh, it were terrible. And then they’d come with that, er... What were it now? That machine- (the vacuum pump)._ 

_Yeah. I’d get woken up at say, seven o’clock in the morning, for my wound management. They were... From seven o’clock... I’d have some breakfast, what you’d fetch me, erm... and then after that it were like I were going to different places. I were going like down there for a scan, up here for summat else. In there. Needles. Needles. I’ve... Me body just couldn’t take it no more. You know? I’d got more... I were like a dart board. I’d got more needles all over me. And, erm... I were getting frustrated that I couldn’t get out of bed._

Michael’s body felt like a “dart board”. His body was an object subject to pain, but was seen to be failing. For a HCP, taking blood from individuals like Michael is often just a mundane task, but for the patient it can hold a more significant meaning; to a HCP the task in hand can itself be seen as a separation of self and body.

The suffering endured by these participants was all-encompassing and some participants reached a point of desperation; they felt they had had enough. As a concept, there were many times during their descriptions of their experiences that suffering became apparent, even though the term was not always explicitly employed. Suffering at this level is not just physical pain, but is often the very essence of illness that is “unspeakable” or concealed (Frank 2001).

Michael recalled moments when he felt very low and desperate. This happened, firstly, when he was enduring what he describes above, and later, when he was transferred back to his own local hospital where he had to stay while he and his wife were being trained to administer his total parenteral nutrition (TPN) therapy at home:

_P: I would have give up._

_P’s wife: In fact, me dad had... they had a bit of an argument, because Michael got to the stage where he just says, 'You should have let me die'._
P: I couldn’t take it any more.

Michael then describes how he feels the family pulled him through by giving him encouragement. It does highlight the enormity of this surgery for these individuals and the psychological impact it can have. The amount of effort and concentration they need just to survive can at times become too much, and this is perhaps the lowest point in the whole experience.

Barbara also described moments of despair; like Michael she was close to just wanting to die.

Yeah, I had lost the will to live. I thought, I just want to go to sleep and not wake up again.

For the other participants the feeling of desperation was not quite as severe as it was for Michael and Barbara, but it was still very significant. Simon endured hallucinations and recounted the effect they had on his perceptions after the surgery.

Mary also described the trough she went through after the surgery. The emotion of waking up and surviving had dissipated, and realisation of the enormity of the surgery was sinking in:

Just when you are low and you seem to get to a point where... straight after the operation I felt, oh this is great. I am okay. I feel great. And then all of a sudden – bang, and I was really down, really low. No real reason, but I think it must just have been the anaesthetic and just the bruise from the operation.

It was difficult for participants to describe how they managed to get through this difficult and prolonged experience. The language used in these descriptions of the suffering was a reflection of the intensity of the emotions provoked. For example, for some participants them pain was always present, and at times became unbearable. Nicola described her pain after the operation and the difficulties with her epidural. She compared the pain before and afterwards:

I am not sure. I think everybody’s experience might be different. Because I know that after the operation I had the most horrendous pain. And it was the worst pain that I ever went through, I think in my life. It was severe. And I know it only
probably lasted four or five days, it was quite traumatic, but I would still have
gone through the operation because the pain I was suffering beforehand, if it
had kept going, it would just have been horrendous. So I would have... still went
through the operation. But I think the pain I went through afterwards, erm...
traumatised me.

Barbara’s description is particularly powerful in her choice of language:

I’d had enough. I’d had enough. I’d got this, erm... this stoma, which was
probably the worst out of the lot. I could cope with having a great big open
wound, but having a stoma. And I don’t know if you know anything about
stomas. But mine was retracting. Because of the sclerosis being so bad they
couldn’t pull the stoma in too far and it kept retracting. So all the faeces
wouldn’t go in the bag, it was burning all my side. So I was red raw. Literally it
was just like I was being burnt alive, and it was just horrendous. In the end,
after having that for about three months, they took me back to theatre, did
some more work in there and closed it. Because it was just... I couldn’t cope. I
couldn’t cope with it. It’s a good job it weren’t a permanent thing because
there’s no way would I have managed.

For Barbara this was a particularly difficult time. She seemed to pause on occasions
and struggled to find the words to explain, the tone of her voice was just heart-rending.

Reflexive diary insert

After listening to all the first interviews I was struck by the enormity of the surgery. I am keenly
aware of the fragility of some of the participants, particularly Beryl, Barbara and Michael.
Listening to some of their experiences of the surgery and the trauma of open wounds and
vacuum pumps, and the desperate situation they found themselves in, I was concerned that I
would not find adequate words to represent what it was like, nor to express the despair they
felt. At the same time I could not help being aware of and admiring their strength of character. I
am not sure I really noticed the language used at the time of the interview, but on reading the
transcript this was only too clear, in particular Barbara’s description of being burnt alive, which
to me seemed to represent the worse possible pain. I had seen pictures of these wounds, but it
only came to life for me when I listened to their accounts.
5.5.2 Bodily awareness – from others and from within

The term "body image" is not used from a phenomenological perspective. As Price (1993) argues, it is concerned with "how people spatially perceive their bodies and how they think others perceive their external size or appearance" (Price 1993). Philosophies arising from a phenomenological perspective view the body more holistically, or as Van Manen (1998) puts it, "the body of self as self-observed". It is thus possible to hide one’s body from others, but one cannot separate one’s body from the sense of self (Van Manen 1998). However, the term "body image" gives a useful frame of reference as to how an individual views their appearance and physical self.

Bodily awareness and body listening have already been described in the present study to describe how participants were aware of their bodies from the pattern of their symptoms, and how surgery caused the body to be objectified from the self. The following examples are closely linked, but demonstrate how the participants and those around them noticed changes to their bodies, making their own body an object of scrutiny. Body awareness in this case refers to its outward appearance.

Two extracts of bodily observation and consciousness from men were quite poignant during the interview. Simon talked about not noticing his weight loss, because he no longer looked in the mirror, nor had he done so since losing his hair. John described his image of himself as so thin and underweight that he had grown a beard to hide his gaunt face. He only shaved it off once he had regained weight. Nicola was the only participant to discuss her PD catheter and its effect on her psychology and what she perceived to be her loss of femininity.

The issue of others noticing weight loss, and trying to hide it from public view, were part of patients being bodily aware and conscious of their appearance, giving rise to embarrassment. Van Manen (1998) describes this as a special relationship with the body, the body being under scrutiny by the individual. Both John and Simon’s it was the result of a change in their outward bodily appearance.

John actually states:
I grew a beard and a moustache, I've never done that before. But the reason was my face was so... There was nothing there. It had gone right in. There was like I had nothing there. So I did it to hide the fact of my illness.

John says he wanted to hide his illness, and the participants generally made reference to wanting their CKD to be hidden from public view. In this way they could restore some normality to their everyday lives without others being aware of it.

Cheryl, on the other hand, spoke about the changes she had noticed due to weight loss, and how this had been disguised by abdominal swelling due to ascites:

*By that time I looked as though I was pregnant as well, even though I'd lost so much body weight.*

Others described noticing it in their clothes and seeing it when they were undressing. All the participants made reference to weight at some stage, and in particular it was regarded as a measure of their recovery, because it had been so noticeable before and after surgery.

Nicola demonstrates how objectifying the body in such disruptive circumstances could produce feelings of disassociation:

*P: The stoma nurse, oh she was fantastic. Initially she did everything, and I wanted her to do it, I didn't want to touch it. I just didn't want anything to do with it.*

*I: Did you look at it?*

*P: I looked at it, but I felt it was quite alien.*

Nicola’s use of the word “alien” confirms that she viewed the stoma as not belonging to her. This is similar to Barbara and Michael, who also had open abdominal wounds and a stoma. Barbara describes how she too could not look at it, and tried to disassociate herself from what the HCPs were doing with her wound. Michael mentions that the surgeon even offered him a blindfold so he would not have to look at his open wound.
The hardest part for Michael was dealing with the open wound, but unlike Barbara and Nicola he seemed to have accepted the presence of the stoma:

I: So just how you’ve coped with that really. How were you when you found out about that? Did you understand it at first?

P: Well at first I thought, Jesus Christ, some more tackle on my body. You know, with having the fistula and what not, I thought, oh not some more stuff. But you just get used... I mean at the end of the day he saved my life by doing this, so I have got to get on with it. And that’s how I feel about it. It doesn’t bother me at all.

The presence of a stoma was described by many participants as something that would be difficult to cope with. Three participants had stomas; two were temporary and one permanent. Michael, who had the permanent stoma, had no knowledge that this would be present, as he had been unconscious when transferred, and he therefore had a different perspective. Many mentioned their concern about having a stoma, only realising that this was a possibility when they met the surgeon.

Even though Barbara was getting on with life, as Michael was, she discussed the issue of how her body had been left following surgery. Following damage to her pancreas, this was compounded by hair loss;

Yeah. I mean I’ve still got a problem. My stomach still hurts because of the amount of surgery that I’ve had, it’s still tender and sore. You know, it’s been
stretched, poked, prodded, opened, stretched and more stretched again. And you know, everything has been moved. And my gall bladder has collapsed and moved over to the side because of all the work that I’ve had done. And it’s just... I’ve got two... I’ve got all hernias now in my stomach and they can’t operate because my body is still, is malnourished. Because with having the operations and the... they disturbed the pancreas, they knocked the pancreas, which stopped my body absorbing nutrients. So I’m on Creon. I’ve lost my hair, which I’ve got a wig now. You know what I mean. I mean, it got me down, losing my hair, because that’s a big thing. And it’s only been since I come out of hospital. I’ve probably lost it over the past three months, gradually. And then you get up one morning and you look in the mirror and you think, where’s my hair gone?

Reflexive diary insert

When I left Barbara’s house for the last time following the second interview she was a lot stronger than when I had seen her at the first interview. Today we further discussed body image, and as a person who had undergone a mastectomy she now had additional issues to cope with. It was particularly meaningful as she and her husband had separated, and she felt it would be difficult if she met someone new. She showed me her abdomen and made a joke about having reconstructive surgery when she goes in for her hernia repair.

Barbara seemed to have significant problems dealing with her bodily appearance following the surgery. For the other participants the body changes were symptoms of EPS, but unlike earlier discussions of pain and gastrointestinal symptoms, this was reflected in their appearance, and in particular being noticed by other people. As Mary says:

P: Definitely. I mean, erm... Every time... I see my mum probably once a week, or something like that, and every... every week she could see the difference.

I: Right, okay.
P: That I’d started shrivelling up like an old woman, sort of thing, as a… for a turn of phrase.

A body that goes unnoticed means that the body is still subjectively part of the self. When it is noticed by another person it becomes objectified, and this can provoke a self-conscious response (Van Manen 1998).

Beryl also discussed how she felt her appearance had changed, not just from the EPS surgery, but since developing CKD. During the interview she showed me photographs of how she looked before she had CKD, and her hair had changed from being naturally curly to straight. She had also lost a significant amount of weight. Beryl kept a constant reminder of how she used to look and felt it important to share that with me. Like the others, she was conscious of the impact of the surgery and scars left on her abdomen:

It’s like I’ve got four scars now on my abdomen and right up to here now. And I said to my husband, you know, ‘Oh, well that’s no bikinis any more’ and he said ‘Yes, but this isn’t about cosmetics, is it? It’s about survival’. And he’s right, you know. You’ve just got to find ways to get through, haven’t you?

The use of the term “survival” emphasises the reality of the situation. Although affected by her appearance and the changes to her body, Beryl acknowledges that endurance and “battling on” are the only way to get through.

Reflexive diary insert

I noticed during the interviews that Beryl often ended her sentences with a question, as though she was looking for an affirmative answer from me to give her reassurance. This may reflect that she is trying to convince herself about what she is aiming to convey.

Simon’s perspective was different, and it is interesting because it forms part of his hallucination. It relates to his body and the concentrated movement he has to make:
It was just so hard. I mean I can remember waking up in HDU and not being able to move at all, just being... everything feeling so heavy that you just couldn’t even move your arm. Right, when I was in HDU, when I say I couldn’t move my arms, I was pushing myself to move my arm. In fact that was part of my hallucination, I’ve mentioned it to you?

I had a... one of the major hallucinations I had was a... I’d look up and there was a transparent ceiling tile and I’d look up and it was a skeleton and it was me, I moved and the skeleton moved – it was me. And the skeleton was just a skeleton, but if I did something it would have more meat on it, it became more like a person. So I’d have to move my head and if I managed... because I couldn’t move anything, and if I managed to move my head by the end of the day it’d have hair and a face. And in the morning when I’d wake up it’d have hair and a face, but I’d have to move my head and something else, my arm. And then if... Like the next day when I woke up if I didn’t do anything all day, it... the skin would come off it and it’d be a skull again.

He interprets being so aware of his bodily movements as a way of getting better. He believes his only choice is just to keep pushing himself. He describes the effort required even to keep breathing, and feels this is part of the hallucination:

Well it would be easier, because it takes no effort, because all you would have to do... Because, I mean you know when you’re struggling to breathe, you have to physically make yourself breathe. You have to... and if you just stop, well it wouldn’t really be a major problem. You know, when you’re... like when I had the breathing tube in and all that, it wouldn’t have been a problem to just stop breathing. I had to keep myself awake so I could keep breathing. But, you know, my wife was in my mind all the time, and everything.

Simon needed a conscious effort to keep going, using the image of his wife as the source of his strength.

Some of the other participants also described hallucinations. Their recollection of them was very real, and not always negative. In Simon’s case its intensity has left him with flashbacks and he has continued to visit the ITU follow-up team as part of his recovery.
5.5.3 Struggles with eating

One of the significant aspects of bodily changes described by the participants is their view of eating and their relationship to food. This was more the case with those that had spent longer in hospital and had only been given nutrition via intravenous routes. Surgery to the bowel means that eating may not normally be possible for several weeks. Barbara discussed how she felt at not being able to eat – and not wanting to do so:

P: I couldn’t even look at food. And I’d be vomiting because of the smell of the food... even the smell of it and the thought of eating, I just threw up. I never thought I would eat ever again. I couldn’t eat, I couldn’t eat anything. They’d bring me crisps. They’d bring me cheeses, little cheeses in things. You know, because there was fridges at the hospital that you could keep... And fruit, and I just couldn’t, couldn’t eat anything. I couldn’t put anything past my lips. And I remember the first thing I think I tried. I fancied a bag of plain crisps and I remember tasting this crisp and it was the saltiest thing I’ve ever tasted because I’d had nothing in my mouth for that long that it was like sticking a bag of salt in your mouth, that’s what it was like. I couldn’t drink anything other than bottled water. And I had a cup of latte, so it was like latte, but I didn’t drink that. And then I just... It was just like... It was just... I can’t explain, it was just so horrendous.

Interestingly, Michael also describes the problem of the salty taste of food; like Barbara, he had not eaten anything for several weeks:

P: I was starving. You know, I could have eaten a scabby horse.

I: But when the food got there?

P: But when the food come, and I put it in my mouth, I couldn’t eat it. Everything I tasted, really strong. I mean, “Jesus, I can’t eat that.” And she said, “Why?” I said, “It’s full of salt.” She says, “There’s none on it.” But I could taste, it’s like somebody had poured a salt pot in my mouth. “Oh,” I went, “oh, I can’t eat that.”
Struggling through this stage required enormous strength of character. Their families played a major role by bringing in food, but often the participants could not even face it, because although they craved certain foods the actual task of eating was too much.

The process of getting through this, and adapting to a new relationship with food, is from an existential perspective an example of the way the body and the self are no longer separated. Simon provides an insight into this perspective:

> Until you find out how your stomach’s working and then, you know, I mean it’s maybe that whoever has just been through the surgery comes out different, you know? But it can’t do any harm by having small amounts really.

> And like you’ve got like the things like I’ve got now, indigestion and stuff like that. And when you... I found after I had the operation, I had a different stomach... The stomach I’d had for fifty years no longer functioned in the same way.

> I can eat a quantity of food, but I find that I have to eat amounts at intervals, every two hours. Before, if I was hungry and I just felt a bit peckish, now when I’m hungry I have to eat something otherwise my stomach actually is quite painful. Not painful, that’s the wrong word, like you’ve got bad indigestion. Yeah, fizzy.

The ways in which Simon describes his new stomach is an example of how he has adapted to this new way of eating. Throughout their descriptions, many participants listened to their bodies and managed their symptoms accordingly, based on their knowledge and experience of their illness.

### 5.5.4 Summary

The lived body was very apparent as a philosophical concept during the study. The existential theme has also been referred to as corporeality (Van Manen 1990, Johnson 2000). The experience of the participants describes in vivid terms the traumatic and painful experience they have had to endure. Endurance was an example of the way they had survived some of the horrific events they had faced. These included major
abdominal surgery, with open wounds requiring frequent visits to theatre, and this seemed like a further assault on the body. For some participants the formation of a stoma and the sense of alienation underlined the disembodiment that may be felt. This emphasised the frailty of the body and the strength and determination required to get through each day. For participants simply eating became a major hurdle to be overcome.

As individuals who had lived with long term condition and dialysis for many years, these events took place as they moved through different bodily experiences, such as being bodily aware and body listening, sometimes to an acute phase of disembodiment. As Van Manen (1998) points out, the disrupted body experience can develop into a meaningful and liveable relationship between the physical and the lived body, and between the embodied being and the world (Van Manen 1998).

5.6 Adjustments and transitions – “A journey of survival”

The final theme, adjustments and transitions, has three subcategories:

- Losses
- Support structures and their impact
- Locating “self”.

The findings so far have illustrated a number of aspects of the experience of EPS that were traumatic and life-changing. The participants had already undergone life changes when they developed CKD. The adjustments they now had to make as a consequence of EPS are important to help us understand the problems and difficulties encountered. They involve the transition between dialysis modalities and how these impacted on lifestyle. The support structures required, particularly families, were an aspect common to the whole experience. Central to this is what has been described as “locating self”, which encompassed a perception of their own belief structures and the strategies that enabled them to survive this long and troubled journey.
5.6.1 Losses

Loss in the context of long term condition has been described as powerlessness (Hummel 2009), and is linked to the various theoretical concepts of suffering, control, identity and security (Strandmark 2005, Aujoulat et al. 2007). For the participants in the present study the experience of loss was related to the difference in functional ability before and after surgery. Loss of control over their illness had been experienced in HD, which involved handing over responsibility to others, and also loss of control while they were in hospital. The loss they felt for PD included both of these aspects, but by moving to HD they had lost the freedom and independence that PD had offered them. After becoming adapted to PD their lives had again changed; now they had developed EPS and had to switch to hospital-based HD.

The functional and physical effects of EPS at times left participants in shock at the way their bodies had “let them down”, and the loss of independence was difficult to accept. This gave them a sense of powerlessness, but it was something they were determined to overcome. So from the initial early days of recovery, when even sitting and walking was an effort, they all described their determination to regain their strength. On the other hand, in some cases the time it took to get back to their idea of normality highlighted the enormity of what they had been through, and even after six months at home they were still recovering.

This is reflected by remarks made by Mary and Beryl, who seemed surprised by the degree to which it had affected their physical strength. Firstly, Mary describes her surprise:

My legs were so heavy, I... That was a surprise. And then when I did get home, I mean we're lucky we've got a loo downstairs, so it wasn't that I had to go upstairs all the time, but just going upstairs to bed, as one step at a time, and you're stopping and er... you know, taking it steady. Erm... But that... was a surprise, and just... just not doing things.

Beryl too says she was not prepared for this reduced level of independence, and indeed how difficult it would have been to anticipate it:
I think I found that hard... I found that hard, not being independent and relying on so many other people. That’s not me really. It’s as if you feel prepared for this, I don’t think you can be prepared for it. It’s taken me longer than I thought, yeah. Yeah, and I’m still not there, you know, by any means. No... I like to be independent and I couldn’t be. And it took me a long time to get to the stage of even being to get... able to get out of bed, you know?

Reflexive diary insert

While listening to the physical and functional effects they all described, and their slow recovery, I became aware of how HCPs should prepare patients for these. Many times during the interviews they said they could not go through it again. I wondered if the focus initially had been on fear of the possibility of dying from the surgery, and that too little attention had been paid to how they would recover once they had actually survived it. They made reference to how in the past they had faced a variety of challenges and had always recovered and got back to normal, but this time it was different and had presented a much greater challenge. The enormity of the surgery and its effects on their body was often difficult to express.

On a positive note, during the second interviews it was clear that all participants felt they were showing signs of recovery, although they remained shocked at how long it was taking. They often referred to earlier occasions when “acute” events had taken place and they had bounced back very quickly. This time the resilience they had previously felt was missing, and they had to develop a sense of coherence and rebuild themselves, not just physically, but also psychologically and socially.

For some participants the loss of independence also meant that their role had changed. A person’s role forms part of their identity and adjusting to a change can be difficult. In the present case the role encompasses the relationships within the family, for example mother, father, husband and wife, and also within society. As Beryl explains here:

So that is still my goal, to get myself back to the level of independence that I did have before. I still lean on my husband a lot and I want to try and lessen that, because he doesn’t need the pressure from me. The reason I say that is because
you know the way men are not multi-taskers, you know, shopping and cleaning and cooking, and picking my son up from the station, and juggling all those sort of things, you know? It’s not... it’s not my husband’s sphere. He does it all, but I want to be able to...

Beryl had a picture of what she ideally wanted to achieve, a goal that was important to her and was an element in who she is, her essential self-identity. This explained the guilt she felt for putting unreasonable pressure on her husband.

Loss of control seemed to arise from a number of participants experiences, in particular from the perspective of being in control of their illness, taking responsibility for their own treatment and even understanding it – sometimes better than the HCPs caring for them. This related to aspects of self-care, for example medications, needling fistulas on dialysis and understanding how they responded to different regimes. Handing their care over to a different HCP could be difficult. The change in circumstances and environment were often seen to be obstacles they could not overcome, or which made them feel powerless. Loss of control was also an aspect of dialysis modality; those who had transferred to hospital HD tended to feel that they had lost some degree of control over their illness

Reflexive diary insert

For me a unique aspect of the study was to discover what the participants would contribute to the experience of EPS. Thanks to my own experience of caring for patients on PD I was aware of the level of control and independence that patients might achieve. I also knew that those on PD were different in that they would have been receiving this treatment over a long period. I was therefore not surprised that they referred to the many aspects of not being in control, something that was not unique to EPS but applied to all patients with chronic illness, making any hospitalisation or interaction with HCPs a challenging experience.

Michael described how he felt about losing control:
I think that’s what the problem were when I were in the city, I didn’t have control of the situation. Where I’m used to having it…. that’s me. I can do that, leave me alone. And you… They wouldn’t even let me take my own tablet.

For Annette, loss of control over her needling became an issue. She did not feel that the nurses had as much experience of it as she did – it was her fistula and she knew best:

I: Do you like to be in control of your treatment?

P: Yeah, yeah, yeah, I do. Yeah, the thing is it’s just like, for example, I’ve got these… I have made these new sites now and I have made them a few times. And even the nurse at the training unit said to me there, that you’ve got to take control of your — if you’re going to be independent, you know? Because other nurses, other people will have different… They’ll go, they’ll make… in one site they’ll be all… there’ll be many sites, there’ll be two, three or four sites, so you have got to take control of the needle yourself and make that site yourself. And that’s right, I found out for myself that, but different nurses will come in and they’ll… you know, they’ll just say ‘Oh…’. And there’s nothing wrong with the nurses, it’s just that you have that one hand, you know your own body.

The needling of the fistula was something Annette felt very strongly about and at times it caused her a lot of anxiety and stress. She had trained for home haemodialysis and became responsible for her own treatment. Her fistula and where the needles were inserted were therefore very important to her and she knew they were her responsibility. To relinquish this responsibility to ward nurses whom she felt did not listen created stress, and it emphasises the level of self-management and independence she was used to and still needed. This was an important issue because the type of treatment she had to undergo at home was intrusive to her body, and the bodily impact of the dialysis therapy is something all renal patients have to come to terms with.

For some of the participants the loss of control related not only to EPS, but to their experience of HD compared with PD. Interestingly, three of the participants in the study are now on home HD and one expressed an interest in going onto home
haemodialysis. They wanted a life that gave them more control and which recreated the level of independence and freedom that PD had offered. Cheryl compared her view of HD treatment now and before she started treatment, and she then spoke about trying for home HD once her fistula was formed.

P: Now I’m on the haemo, I’m just so tied, just don’t like it.

I: So is haemo... you find that restrictive time-wise?

P: Yeah. And to be able to get away. Erm... And I... I mean I always think about myself, don’t I? It’s like Tuesday, Thursday, Saturday, well we’ve still got the caravan, and I can’t really go now. It’s in Wales, so it’s always booked up, for dialysis in Wales, because they book the year before. So when you want to go on dialysis...

No. I hoped I was one of these that was going to last fifteen, ten or fifteen years on, erm, PD. Never fancied the haemo, actually.

I: Is that from the beginning? You had a view about that from the beginning?

P: Yeah, I didn’t want to be tied in. I want to do things. I hate being restricted. Erm... Just don’t like being sat in a hospital bed for... Well, it can be five hours, can’t it, if not more by the time they’ve set you up.

Many other participants referred to the times and restrictions imposed by HD treatment, the transport involved and the need to rely on other people. Like Cheryl, Mary describes how HD was never really an option for her; she had had a negative view of it until she started on PD:

P: I don’t know if I mentioned it, but initially I felt HD was, erm, the last resort, and...

I: And where do you think that came from?

P: I don’t know. I don’t know. I think it’s... I mean I... Thinking back I probably knew that people opted for HD straight away, but that wasn’t a choice for me, it was PD and then build up to HD, because that was the last... as I say, there was the last resort, although now I realise it’s not, you know... And just the... just the
haemo. I don't know, just... it just revolted me. Not revolted me, but just the thought of it, I just didn't like the thought of it, you know having it... the blood taken away from me, and then brought back clean.

Interestingly, Mary has meanwhile successfully trained on home HD, despite losing much of her eyesight following the surgery. This provides an example of the need to move forward, to overcome previous fears and to adjust to new circumstances, but the focus remains on independence and control.

During the second interview with Beryl I posed a question based on her view of HD. Like the other participants she had negative feelings about it:

I feel less in control now. I feel as if I've handed my life over to other people now and I really liked, you know, the independence that I had before. I would really like home dialysis.

This is very similar to Barbara’s description of the loss of control:

P: Yeah. It was, it didn’t rule my life. HD rules my life. PD, I’d go Turkey, Portugal, Tenerife, I’ve been all over.

I: So you were very independent?

P: Yes. With HD because it’s messing with your blood and your fistula, you’re just, you’re not in control. With PD you’re in control yourself.

The clear distinction between life on PD and on HD had for Barbara created the greatest problem of adjustment. This is not to imply that she could not achieve a certain degree of independence and control, but it would never be quite the same.

Their past experience of CKD had given all these participants the conviction that they were able to achieve a certain amount of independence. They perhaps now faced more limitations overall, and had other restrictions in their lives, but they all had a sense of knowing where they wanted to be.
Reflexive diary insert

Having just left Beryl’s house after the second interview I am conscious of how much time we have spent discussing home HD. I really feel for Beryl, as she lives in an area where home HD opportunities are limited. I am used to a very strong home therapy programme in which home HD is offered to all those who want it, and we have been particularly proactive in encouraging patients to transfer from PD to home HD. I pointed out to her how she might pursue this, for example through the Kidney Patients’ Association and by discussing it with her local team. The NICE guidelines and other DOH documents certainly recommend home HD. I knew that although this was a research interview I could not leave without giving her this information.

Barbara had had the biggest struggle with the transition from PD to HD. I wanted to discuss home HD with her but she immediately said that she could not possibly take it on. I left the discussion there, but if I were her clinician I would have encouraged her and discussed it in greater detail.

Loss of control is very much a factor in the transition from PD to HD. All the participants in the study had experience of PD, and after EPS was diagnosed had transferred to HD, apart from Nicola who had undergone a transplant while still on PD. The loss of PD was something that many participants resented, as it was a time when they had felt well and had a degree of independence. They were able to work and go on holiday, and in general found it a positive experience. It was also clear from the participants that not wanting to switch to HD was a conscious factor; they tended to resist it even after advice from HCPs. For the participants in the present study this is a relevant issue, as it could possibly have contributed to them developing EPS, although this is not supported by hard evidence. It does however highlight the importance of educating and supporting patients in the transition between dialysis therapies.

Mary effectively summarised her reluctance to switch to HD:
I was quite adamant that... Yeah. I mean I did need to be sort of coaxed into it. You know, I probably was on PD longer than I should have been, but just till I got my head round it, really.

“Getting her head around it” is an important point. Ideally the switch to HD should be planned and time given for patients to adjust to the change in their life and routines. For Barbara the situation was even worse as she was having complications with her therapy – but she still did not want to let go:

So we kept trying to keep me on PD and it just didn’t work. It felt that people didn’t know what to do with me when things were going downhill, and they kept trying to make PD work. And I think because I didn’t want to be on haemo I think they kept trying more and more, and I wanted them to try. Instead of removing the tube, he wanted to try and save it if he could and that became a bit of a nightmare in the end.

At this point her husband added his view about what happened when Mary had surgery at their local hospital:

And so they decided ‘Okay, let’s go back’, because she wanted to go back to PD. So they put the catheter back in, but when they opened up they saw it was severely calcified and cut big chunks of the peritoneum away.

Reflexive diary insert

When Beryl’s husband described what happened, alarm bells rang. Had the doctors actually observed the early signs of EPS, as they had to remove calcified peritoneum? And if so, why did they continue with PD? The only logical conclusion was that they weren’t really aware what they had found.

Wanting to remain on PD and not letting go was a major issue for the participants who described the time they had transferred to HD. To them this seemed a negative step, but they were left with no choice. The reasons for the transfer were clearly explained
when they described their experience of PD, even though they were now aware of the risk of EPS. Some of them thought that they might have been too long on PD, and that coming off sooner might have reduced the chance of EPS. According to Simon:

*I mean I had six good years on PD. We went on cruises, we went on holidays. You know, I managed to do a bit of work, you know, so I can’t complain really. But if they would have taken me off peritoneal dialysis after four years and put me on haemo, I wouldn’t have had to have the operation. That would have been a better option I think, you know? But there again, hindsight is a wonderful thing, isn’t it?*

Annette also felt that she had been left on PD too long, and yet she too described how she had resisted the switch to HD for a long time. She felt strongly that her decision might not have been fully informed, but she was not sure if that would have changed her decision to go on to PD, as this had given her freedom and flexibility and left her feeling well. It is difficult for patients to recollect how well they felt on PD, but they accept that this might have been a factor in their developing EPS. This is how Annette describes it: provision of information is once again a factor:

*I felt... Yeah, I felt normal, I felt energetic. Yeah, I went... I was going out at eight and coming back at six, seven, there was nothing wrong with me. I mean obviously the night PD, yeah, yeah, so, and I thought ‘Well, this is a good way at night time, I’ll just put it on and norm... and everything’s back to normal in the morning’. So, but obviously the end result... [laughs]... and long term isn’t, you know? This is it you see, if I knew I could have done something about it. I would have said ‘No, this is quite enough. I’ve got these symptoms and it might be because of, you know?’ So it’s the information is so vital. Yeah. You have to provide that to patients, I think that’s their right, anyway.*

John also struggled with the idea that PD had caused his EPS. He knew that PD had worked well for him, and he had remained employed, but he now wondered whether he should have gone on to it at all. He was adjusting to the restrictions of HD and he was now more reliant on other people, but he accepted that it had been PD that had caused the EPS.
The length of time on PD was often mentioned by participants, and they often asked me about it directly at first. Although not reflected in the interviews, I began to realise it was something I felt strongly about. The length of time on PD is a known risk factor, and when they described being told they had been left on too long I suppose I became defensive. I tried to answer their questions honestly and with emphasis on the lack of strong evidence in support of the theory, and that there might be other factors to take into account. Being told they should have only been on for three years created the concern and doubt they had. The majority of the comments seemed to come from the surgeons and not from the HCPs responsible for their care in their local units. I often wondered if when dealing with a rare condition the surgeons become overwhelmed and see it as common, so therefore forget that many individuals don’t actually go on to to get EPS. This once again emphasised the lack of knowledge and understanding once the symptoms became apparent, but most of them were on HD by that stage. I also was conscious of how challenged some of the participants found themselves in not wanting to make the switch to HD. However the length of time on PD has to be balanced with lots of other clinical factors and there are guidelines specifically published to assist clinicians (Brown et al 2009b). Addressing this very issue is a consideration all health care professionals need to face but remembering the rarity of EPS compared to other high risks of CKD.

When some participants described their experience of PD they spoke of not letting it take over their lives. Two participants used these actual words. The fact that they could describe how they worked through some of the negative aspects was also significant. The positive experience of PD is reflected in how it fitted into their lives, how much they could do, and how for them life could be “normal”. As Cheryl describes:

*PD, even though it ended up causing all these problems, I couldn’t have done without it, because of the freedom. And my thing is, I had six and a half years with the kids, that I could get up, get them to school, see to them, be there for them, go away with them, and things like that.*
Cheryl went on to say she would go back on PD if she knew it would not cause any problems. She knew that this was physiologically not possible, but she had had such a positive experience of PD.

Barbara had similarly strong feelings about PD; for her it was the time when life had been at its most normal since CKD was diagnosed. Barbara describes how passionate she feels about PD:

*When they said to me, ‘Oh you could get EPS and it’s horrible,’ and I thought, well I’ll be the one that don’t get it. But I was on PD for 12½ years and that suited me. I mean I’d have done another 12½ on it if I could......... I hate haemodialysis, it don’t suit me at all. I don’t like it. And if I could have an artificial peritoneum put in I would go back on CAPD, definitely, I would.*

PD gave participants the opportunity to get back to normal, to keep working, go on holiday and care for their family, and they also felt well. They did not describe the restrictions of the technologies involved, and this is significant. They were looking back and comparing that period to where they were now.

**Reflexive diary insert**

Barbara has provided some very powerful statements on her views of PD. The reason I have been so surprised by this is that of all the participants she has spent the most time in hospital, has had horrendous complications and seemed to have suffered enormously. But she still feels she would go back on PD. I have used one of the quotes from her interview at a conference to try to get the message across as to how our view as HCPs is often not matched by those we care for. Anyone who would have read her case notes and looked after her in hospital would I am sure be astonished. However for this study, past experiences cannot be forgotten and are an important element in the participant’s “lived world”.

In summary, the losses felt by the participants in the study were related to independence, control and their time on PD. Remaining independent was a positive aspect of the long term condition experience and participants were unprepared for the impact of EPS, and how it had left them weak, reliant on others and offering such a
slow recovery. Having control of their illness was also important; they understood well the regimes, their own bodies and how to manage their illness. Being in hospital and relinquishing some of this control caused stress and anxiety. The loss of PD and transition to HD was also a difficult period of adjustment. Letting go of PD meant saying good-bye to the period in their illness experience that had been the most positive. For some participants, on the other hand, the transition to home HD had provided the opportunity to regain some control and independence, but for those undergoing hospital HD the restrictions still made a major impact on their lives. However, all participants demonstrated resilience and stoicism as they continued to strive to get back to their concept of normality and to regain their role within the family.

Reflexive diary insert

For me personally the impressions given of PD were very significant. Before commencing the study I had a preconception that patients might feel angry about the therapy that had caused the EPS, yet I knew also that as a group they would have managed their self-care treatment for many years. I was initially struck by the positive experience provided by their time on PD. On the other hand I appreciated that I was seeing them at a vulnerable point in the course of their illness, and when recovering from such radical surgery it is not surprising that they think back to the most positive time of their CKD, which was during PD. I was interested in their view that when preparing for PD that was the stage at which EPS should be communicated. This was always going to be a difficult subject, and although some participants gave frank opinions, it did not really answer the questions I had in mind. It did however give a useful insight into why it is such an issue.

One aspect that came across but which was difficult to interpret was the fact that they clung on to PD. When they described their care towards the end of their time on PD I could hardly believe this, but I realised that the choices and information they were being given did not properly describe the risk they were taking of EPS.
5.6.2 Support structures and their perceived impact

Families played a crucial role, helping participants to get through EPS and were a constant source of support. Although the focus was on EPS, on many occasions the participants referred to their families and the impact CKD had had on them. This created guilt, and participants described how they had tried to protect their family from the consequences of their illness. The study did not set out to include the family, but the wife of one participant joined the interview, and another invited her husband into the interview, as towards the end she wanted him to contribute. The relationship with the surgeon was often referred to and it was clear that this was centred on trust. There was little mention of the supporting role of nursing staff.

The role of families and work colleagues are an important aspect of adjustment to long term condition. Some participants found that their role within the family unit had become threatened, creating feelings of loss, anxiety and stress.

Reflexive diary insert

Having completed all the first interviews, one remark repeatedly stands out: “I couldn’t have got through it without the family”. Although HCPs have been discussed, the overriding universal support they have received has been from their family. This overshadowed the support coming from nurses, the surgeon or the surgical team. This may have been due to the fact that they knew I was a nurse and did not want to go into too much detail, but on the other hand if it had been a positive element I assume that they would have mentioned it. When I did ask about the care provided by nurses, this was usually just dismissed as, “They were very busy”.

There were countless examples in the interview data that could be used to describe how the family had “pulled them through”, providing the support and the determination to carry on. When talking about their families this was often the most emotional part of the whole interview. Specific words of encouragement were recalled, as recounted by Barbara:
But my kids just, they were never, they were always positive. They was always like, you know, they were like on the phone to me saying, you know, ‘Come on, Mum, you’ve got to get through, you know, you’ve got a lot to live for, you’ve got this, and you’ve got that, and my two boys and my daughter-in-law would come and see me and they’d keep, you know... you know, you’ve got to pull through, Mum, you’ve got to fight it, you’ve got to fight.

I feel lucky that I’m still here, and it was the kids who made me fight.

The emotion of having the family as support, and the impact it made on them, was often referred to in the interviews. In a similar way, Annette describes how her children provided support:

And it’s the children, the children all immensely supported me so much, you know, my own children, my own family. More than even my brothers and sisters, you know, they... my own children. Because... I think it’s because, obviously they need me and they want me obviously at this point in time, and they don’t want anything bad to... you know, to happen to me. Especially at this time [laughs]. No, it’s just that they do care for me.

Participants even wondered how people could get through it without the presence of family. Michael describes this:

P: And I feel a lot sorry for people that haven’t got that family support. You know like obviously somebody’s got to have gone through what it was probably... they might be older and not got many family. But I think sometimes I wouldn’t have got... I wouldn’t have got through it without [his wife] or her father.

P’s wife: I think you needed that push.

P: And her father had said, ‘I’m going to keep with us, I’m going to keep you’. And it were just something he said.

Michael was not alone in describing his family having to push him onwards.
Sometimes the support was described as an awareness, just knowing that somebody is around was enough, not only at the EPS stage but throughout their illness. Cheryl summed this up when she spoke of her husband as her source of support:

_He’s not... he’s not good with words or anything like that, but he’s always there._

For Cheryl the shared role and support he provided was often of a very practical nature:

_P: Yeah yeah. And, because as I say, my husband there, he does a lot. He'll... thinks nothing of doing the washing, putting it on the line, washing the pots, giving the kids their tea. It's just practical things._

_I: Yeah._

_P: He'll come home from work, if he's not busy, and then he'll say, 'Do you want to go out somewhere?', if he knows I've been sat here all day. Erm... And we'll go out and do something. Erm... And... Yeah. Even though he's not a really strong person in... as being strong he is, in the way that is... he's there._

The understanding between Cheryl and her husband did not involve words; simply his presence and his ability to think of her needs were enough.

For those participants who lived a long distance from the hospital the family members were often allowed to stay with them for long periods. Some stayed in hospital accommodation which allowed them to spend time with the participants. John and Michael described how their wives actively assisted with their care, providing help and allowing them some dignity.

All the participants felt guilty at what their families must have had to go through, seeing them so ill before the surgery, feeling helpless at not being able to do anything, and then waiting around after the surgery. They even described times when family members or friends did not recognise them when they came to visit them in hospital. There are many examples in the interview data of how the guilt was interpreted. The worries and anxieties it causes can create a feeling of helplessness, as Simon describes:
P: And it must be a pain being with me... She’s had thirty years of me being ill. You know, I mean it’s... people that are ill have it easy. I’ve not really felt sorry for myself, to be honest.

I: No?

P: No. I’ve felt sorry for my wife a lot, she has to put up with me, you know? Which is a worry, you know? And that’s the worst part.

I: It’s the people you leave behind, isn’t it?

P: It is, yeah. And dealing with the... You know, I mean how’s she going to manage for money and stuff like that? I mean I don’t bring a lot in, but you know what I do bring in, through benefits and stuff helps pay the mortgage. So what’s going to happen there, you know? But, you know, it’s just a worry, but there’s nothing I can do about it.

Earlier in the findings, when describing death as a possibility, Cheryl expressed her concern about the impact on her family. This included her fear of leaving them behind, but also the guilt of putting them through so much worry.

Guilt was also associated with the very practical issues that the family had to deal with while their relatives were in hospital. This was particularly relevant for those who lived a long way from the hospital. Participants made reference to the additional costs of travel and accommodation. In particular the room offered in the hospital had little provision for cooking and was a long way from the ward. This was also an issue for those with children and other relatives left at home.
Reflexive diary insert

The impact on the family was a factor that caused a lot of emotion, and being a wife and mother myself I could understand the concern many participants expressed for their children – trying to protect them, and worrying about the impact it was having on them. Guilt is a strong emotion and particularly difficult to deal with. From a healthcare perspective the family is often on the periphery, and yet in chronic illness they are an integral part of the whole experience. I did not set out to interview family members, and only one participant had a family member present throughout who contributed to the interview. It was therefore difficult to draw any conclusions from the perspective of the families, but for the participants it was in many cases their greatest concern. Practical issues of travelling, accommodation and support were raised, and they wanted to make sure that this was recognised in the study. It will feature in the recommendations and feedback given to the ward and other staff responsible for their care.

Some participants described how they protected the family from all that was going on. This was one way they could try to control the impact and the worry of EPS. This not only concerned their children but often the wider family. It also reflects how difficult it can be for people to discuss their emotions with those closest to them – in particular the fear of dying. Cheryl describes how she often kept her illness from the rest of her family as a result of the way they dealt with it:

P: *I can’t be doing with the reactions, the way they are. The fact that you know as soon as you’ve told them they’re going to be depressed about it.*

I: *Yeah.*

P: *And it’s going to be on their mind all the time. And I don’t want that.*

I: *No.*

P: *I want people to be like me.*

The statement, “I want people to be like me” signifies a strong sense of “self”. Cheryl explains there are still people who do not know about her cancer or illness:
Because I'll see people, and they'll go, 'Oh you're looking really well now'. And I just can't bring myself to turn round and go, 'Oh, I've just had my breast off, got breast cancer. It was in my lymph nodes'. I just can't bring myself to say it, because they say, 'Oh, you look so well', and I think everybody's been through so much, hoping that I get better, that they must think, 'Oh my God, erm... the poor girl, what's she doing going through this as well'. And I don't want all that.

Being optimistic about her illness, Cheryl wanted those around her to feel the same. She did not want sympathy, or the awkward moments that can often occur in such situations. This protection was something that mothers tried particularly hard to achieve, keeping from their children the realities of the illness in the hope of retaining normality for them. Making sure the family was financially prepared made a strong impact on the men in the study, emphasising their role within the family unit. The constant struggle for many of the participants of the impact their illness was having on their family was one of their biggest worries.

Some participants also alluded to their beliefs as a support structure. Spiritual beliefs were often a very important aspect of their illness experience. For Nicola this only came out after we had finished the interview, and I recorded it by writing it down after I had left the house. She talked about the prayers that were said for her while she was in hospital, and how she gained strength from knowing this. Beryl also described her religion as a source of strength and how her belief in an afterlife made her calm and less frightened of dying. Spirituality was therefore a source of strength for some participants and provided hope. It was integral to their belief that they would get well, and this relieved their suffering.

In summary, support from the family was universally regarded as an essential component of the experience. Families provided encouragement and were a source of strength. Along with this came a feeling of guilt, being conscious of what the family was going through and the anxiety the patient was felt to have caused. One of the most poignant moments in the interviews was when Michael’s wife described his journey going from his local hospital to another hospital for treatment. Her account of his journey in the ambulance when he was critically ill, and how she saw the ambulance pass her en route, I found very emotional. The impact of EPS on the family
was not part of the study, but as an individual listening to their experiences it is only natural to wonder what they must have been going through. When reading and listening to these accounts there is no reference to the HCP as a source of strength, in fact there is little emphasis on anyone other than the family. It has been observed that early in the experience they had lost some trust in HCPs when their reported symptoms had not been acted upon. Negotiating with HCPs was one aspect of how they had become expert in the management of their illness, and feeling let down by them reinforces any doubts they may have about the relationship.

5.6.3 Locating “self”

Locating self relates to the belief structures and gives a sense of the strategies used by participants in their experience of EPS. For many, their experience of EPS was inextricably linked to their long term condition. There were many times during the interviews where comparisons were made, usually associated with life changing events, following their diagnosis of CKD and then later EPS. They described how they thought their own abilities and characteristics had equipped them to adjust and cope with this. The unique situation of these participants in their “life world” of living with long term condition, and the impact EPS had on them, cannot be underestimated. Their personal attributes can be deduced from the way the participants described their determination to cope and, as has already been described, their need to remain independent and in control. How they view life now takes on a different meaning than previously, and their “feeling lucky to be alive” becomes existential in its new meaning.

Being strong and being positive were common phrases used by the participants. In order to understand how the “self” is viewed it is important to analyse the perspectives and experiences of these participants as to how they have adjusted to long term condition. This gives an insight into their ability to cope, and how they have achieved this despite the difficulties along the way. Simon in particular often gave great insight into living with his long term condition, which he had had for 30 years:

*You know? Try... the problem with illness is, is that when you walk down the street you’re looking around you and you see the trees and the birds and
everything, and you’re looking out. As soon as you’re ill all your conceptions go
in and you’re looking in, and you don’t look out anymore, you don’t notice
anything around you. And for the people around you that’s very difficult,
because you become reclusive and they think you’re being awkward and you’re
being sullen, and everything like that. And it’s very difficult to break through
that when you’re feeling ill and think, you know, ‘I’ve got to stop this, looking
into myself and being... feeling sorry myself, looking inwards’. Because all you
feel is like the pain or the discomfort, and you focus on that and you forget
about everything else. And if you can get to the point where you just accept that
that’s going to be, and still look out and look around you. That’s the trick.

Simon no longer noticed the world around him, and this is interesting. From an
existential perspective it relates to “the body of self as an aspect of the world”, as
described here:

We may first discover that we are ill, not because we feel body symptoms, but
because we notice how changed aspects of the outside world become
symptomatic of something that must be wrong within us’. (Van Manen 1998).

The pain and discomfort of the illness have made Simon more bodily aware, and trying
to control the emotion and to see the world around as normal have become extremely
difficult for him. This is part of the process of learning to live with long term condition.

Simon describes how life has now become:

Well, I mean you’ve got... in my case, you’ve got dialysis. You’ve got... people
keep telling me I’ve got a dodgy ticker. And I’ve got this as well, and some
people I suppose have got diabetes as well, haven’t they, and other things. But
it’s just another thing isn’t it, you know? And it’s... It seems like, you know, on
haemodialysis you might get a day, maybe two days out of the week when
you’re feeling reasonably all right. With this you get maybe one day, two days
out of the week when you may be feeling reasonably all right. Now if those two
days coincide, you get a couple of days, but they don’t usually. And the days
when they’re bad, both together, you feel pretty grotty, you know? But
occasionally you do get a day when they’re both all right and you feel on top of the world, you know.

You have to adopt a different mindset to cope, because you’re not looking forward to a day when you don’t have it. What you find you end up doing is looking forward to a day when the symptoms ease off, when you feel more normal. So you end up really accepting feeling grotty as the norm.

Simon used the term acceptance in relation to what is now his new “normal”. From his perspective this reflects the very essence of living with long term condition. The reality of the illness is always present and it cannot be ignored; it is how an individual now views life and enables an individual to live with a long term condition.

**Reflexive diary insert**

Early in the study I made notes on survival, and how these participants had battled through the enormity of the difficulties EPS had caused. I knew that to tease out EPS as an experience on its own would not always be possible, and this is why in the aims of the study I had phrased the question, ‘in the context of their chronic illness’. From the outset I saw EPS as an acute challenge that had to be overcome. I was however surprised by the depth of the insight they revealed, particularly Simon, whom I had known in the past as patient. I sometimes wonder whether we pay no more than lip-service to the psychological needs of our patients, when we can learn so much from them.

Many other participants gave their perspective of how they had adapted and coped with CKD. Nicola described her early anxieties and difficulties of coping and how through her determination and her spiritual beliefs managed to get back to work and achieve a normal life:

*Well I think what I do have is... certainly from the dialysis I live my life to the full. You know I went on holiday. I went swimming. I did everything that everybody else done. I just didn’t let it take over my life. I sort of ruled the dialysis, it didn’t*
rule my life. And certainly with this, it is there, it has got to be there just now so I just have to get on with it. I think that... The way I feel about renal failure, you know end stage renal failure, now that you have got it there's nothing you can do about it. You can't change it. So you just... You either sit down and feel sorry for yourself and don't really get on with your life, or you say to yourself, 'Right. I need to get on with life'. And that's what I done, just got on with life. There's isn't anything else for it. So I think that's... And I think work as well, because when I first went to the clinic here, because I had been at a hospital down south for a long time. I moved up north and started going to a new hospital. I think the doctor was quite shocked that I worked, and that I worked full time and the type of job I done and... I just didn't see it as any different.

Nicola's description of coping, not feeling sorry for herself and essentially getting on with life was common. For Nicola, being able to work allowed this to happen. Work seemed an important measure of getting back to “normal”.

The personal attributes of being strong, stoical and positive could be regarded as coping strategies for achieving adaptation and adjustment. However, most participants described them as a feature of self-belief, and part of the social and psychological aspects of their illness. It also demonstrates how overcoming illness is hard work, and how participants have constantly revisited the challenges they have faced previously. It certainly seemed to equip them for the struggles and difficulties that EPS brought into their lives.

Reflexive diary insert

Listening to the participants’ accounts is a reflexive experience, because both as a nurse and as a person I often think: What would I do? I am sure they reflect many patients’ attitudes, but not everybody copes in the same way. So what makes them unique? I can only look at what they regard as personal attributes and behaviours that they adopt to get through each day. Understanding this concept is something I have read about and have seen in practice – but listening to their first-hand experiences certainly brings reality to that knowledge. What attributes can we detect in this group? And these something that can be taught?
The struggles the participants had faced with EPS, although daunting, were not overwhelming and they believed they had the strength of character to overcome them. Some of the attributes have been described within the other themes, including the fighting spirit when faced with the surgery, the endurance needed and the desperate moments that occurred. Their determination and the way they had managed their illness themselves were clear, and the sense of doing it oneself and not relying totally on others seemed an important issue. As Mary described:

And you know you've got to chase things up. You can't rely on people to do things when they say they're going to do it. So I think that's probably helped with me chasing up my tests and, you know, pushing for things. Erm... And yeah, just... just for you to feel well, and to... you know, it's all down to you, isn't it? No one else is going to do it. So you've got to do it yourself. Erm... And like I say, I'm a bit stubborn that way, and you know, I'll persevere until I can do it right.

Mary was clearly a very determined person. She had always gone back to work again, and even with the difficulty of managing diabetes and dialysis at home, then partially losing her eyesight. This determination had continually given her the ability to manage her illness herself. It is important to realise what an effort this has taken, and that while participants describe these attributes they also admit that they have times when they feel low. However they consciously push these thoughts away and think positively, looking for positive stories and keeping themselves busy. Such optimism gives individuals the necessary resilience, as Annette highlights:

Yeah, I’m just an optimistic person, I’m that kind of a personality, I always look on the bright side. So I’ve never looked on... You know, even if I did think for a while that I’m going to die, I al--... even from that I’ve... you know, I was always looking on the bright side, I was looking optimistically. You know, I’ve got some chance of living and I will, I will come through, you know, through this. Yes. Yeah.

Cheryl similarly describes the need to keep hold of the positive:

Because, as I was saying, I'm just going to keep fighting, and hopefully the tamoxifen... Every now and then I'll read a nice story, or read a bad story, and then
I... I grab on the good one, that people have had mastectomy, had lymph node clearance, been on tomoxifen and they’re still alive seven years later. So...

Weighing up the current situation is a feature of the self being located within their world. Even after desperate and enduring experiences, the new adjusted self views life differently. Overcoming suffering and near death experiences provides a different outlook on life, and “locating self” leads to an existential view of life. As Simon puts it:

Yeah. But that’s because of my personal circumstances. I’ve got a family that loves me and, I mean I’m skint, we haven’t got two halfpennies to rub together. The whole house needs decorating. So, you know, we’ve... there’s a lot of financial worries, but I think when you’ve been through something that might mean that you’re not there, just actually... you know, being there...

The existential concept of “just being there” is a sign that the lived world is now being viewed from a new perspective. Simon describes his new outlook on life and “feeling lucky”, as did many of the other participants. This is often an emotional time, particularly when thinking about others, as they recall how lucky they feel. Acceptance of the suffering imposed by EPS has given them a new perspective on life. This was very poignant for Barbara, who had witnessed others die, in particular someone she had got to know before the surgery:

P: Mm, yeah. And I thought, you know, it’s just awful think that... And then I think well, I’m lucky. I pulled through it. They weren’t the lucky ones. And I felt really guilty because he ended up dying... And he looked so ill. And his wife was there by his side all the time. And they’ve got kiddies... They’ve got two little kiddies.

I: I know, it’s very sad.

P: I mean mine were grown... Like I mean my... I’ve got two boys, 17 and 26, so mine are like, they’re older. But you know, even so.

So for Barbara there was also a sense of guilt when she thought about the patient who had died. Seeing others with the same illness could either create anxiety or hope. As a group these participants will have encountered a large number of other patients with
CKD; however it was only Barbara who described meeting others who had EPS, and she realised that they had all died. So her feeling lucky had a slightly different perspective because of the guilt she was feeling.

The other participants often just described it quite simply as taking each day at a time and feeling that every day was a bonus. Michael describes how he felt when he heard the account of his experience from his wife’s perspective:

I: And listening to your wife retell that... that whole account. How does that make you feel, listening to that?

P: That I were lucky. How lucky I were to survive and then... [becoming upset]

I: It’s OK. [pause]

P: I was er... I will never forget them.......I always said it would be dialysis.

I: Did you?

P: ... and it hasn’t.

I: No. No it hasn’t.

P: Just get on with life now. It weren’t my time. I must have got nine lives, like a bleeding cat. Because I’ve used six of them up with things. But what they tell me like but... I think I am very lucky. Very lucky.

It was emotional for Michael, and he started to cry. He described every day as a bonus, and this was reiterated by the others. The heightened appreciation of things around them, and the family, added to Simon’s feeling of being lucky:

Yeah. I appreciate more things now. I don’t take so much for granted as I used to. A bit more creepy. My wife tells me off for staring at her. Yeah. [laughs] ‘Stop it, you’re creepy!’

Being close to death and facing the prospect of leaving their families behind leads to a reappraisal of life and life situations. This can only be described as a positive feeling, since although there is still a fear of the future, coming through something so
devastating has left participants with greater determination and strength. They have put the experience into the past, as Barbara says:

“I don’t dwell on that. No, it’s part of my life that had to be done. And it’s... it’s done, done with, gone now.”

Few participants mentioned planning for the future. They still had goals, but understandably did not want to look very far into the future. Their goals were often expressed as functional abilities, levels of independence and control of their illness.

5.6.4 Summary

The adjustments and transitions resulting from EPS can be viewed within the context of the participants’ overall experience of long term condition. They have applied this in a number of ways when faced with the challenges of EPS. The participants provide a fascinating insight into how their coping mechanisms have been applied.

EPS is an enormous challenge, one of the biggest the participants had ever had to face, but the support structures that have been put in place, together with the many positive attributes demonstrated, are vital elements in the readjustment process.

These findings are a reflection of those reached in other studies, in that when faced with severe health problems the adjustment to illness can be viewed as a process of maintaining a positive view of oneself and the world (Sharpe and Curran 2006). CKD as an illness involves the technical aspects of care, self-management and the transition between dialysis modalities, but in the case of EPS fundamental issues of life and death take centre stage. It was encouraging that so many participants viewed the fact that they were still alive as a bonus, and this positive attitude implies that they have found new meaning in their long term condition. Ultimately for these participants this has truly been “a journey of survival”.

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CHAPTER 6: DISCUSSION OF THE FINDINGS

6.1 Introduction

The primary aims of the present study were:

- To explore patients’ understanding of EPS in the context of their “life journey” on dialysis.
- To examine the meaning and impact of the condition, as constructed by individual patients.

The Objectives therefore are:

- To explore patients understanding of EPS, including their condition-related knowledge and information needs.
- To explore the symptoms of EPS as perceived by patients and how these are considered to have impacted on their lives.
- To explore patients’ views of PD as a therapy.
- To explore the perceived impact of the surgery for EPS as an ‘embodied experience’.
- To explore support structures and mechanisms used by individuals following the diagnosis of EPS.

All the participants were very keen to convey what it is like to live with CKD and the impact EPS has had on them and their families. The study has consequently generated a large amount of data and discussion of the findings will necessarily be limited to those that most directly address the research aims and objectives and those which provide a platform for informing future clinical practice. Some of the themes from the literature review (Chapter 2) resonate strongly with the findings of the present study, and will be incorporated into this discussion where appropriate, whilst areas of divergence or contrast will also be highlighted.
Five areas are addressed in the discussion:

1. Gaps in Knowledge, Expertise and Communication
   - Communication and Information
   - Early Recognition of Symptoms and the Problem of ‘Not Being Heard’

2. Embodiment - The Impact of Surgery

3. Transitions - Views of PD

4. EPS: A Challenge within a long-term Condition

5. The Importance of Support Structures

### 6.2 EPS – Gaps in knowledge, expertise and communication

A major finding of the present study, and an important issue for clinical practice, was the clear lack of knowledge and understanding of EPS on the part of participants and, seemingly, also amongst healthcare professionals. The majority of disease processes and long term conditions have a pre-diagnostic phase, and EPS is no different.

However, EPS is an iatrogenic disease – it is a consequence of one type of dialysis (PD) used in the treatment of CKD. For all, but one of the participants, the symptoms of EPS arose after they had transferred from PD to HD, the exception being one who showed symptoms of EPS following a transplant. Initially, symptoms were noticed casually by the participants and their significance had not registered. This suggests that although most were at risk of developing EPS, they did not know they were at risk and were unaware of which symptoms could be regarded as relevant. Perhaps more worryingly, there was a perception amongst participants – typically supported by their experiences of diagnostic delay - that the HCPs involved in their care either did not recognise the symptoms of EPS, or failed to make the connection between their having been on PD and the possibility of their developing EPS. This led to widespread feelings amongst patients of isolation, of not being listened to and of feeling neglected. These issues
concern information-giving, communication, knowledge and expertise, and each will be considered separately.

6.2.1 Communication and information

The gaps identified in this study on communication and information need to be considered in the context of the current understanding of the risks of developing EPS, this can then be related to how, when and why EPS should be discussed with patients.

In Chapter 1 an overview of EPS was given and the incidence of the disease across the world was presented (Table 1). This forms the starting point for the epidemiology of EPS and the information that could be made available to patients undergoing PD therapy.

A study in Scotland has attempted to address this by discussing how the risk can be communicated to patients (Brown et al 2009c). According to Brown’s data after four years on PD there is a one in twelve chance of developing EPS. The authors do not describe how the risk information can be communicated but do highlight the challenges, recommending at four years, a young patient who is suitable for transplantation should be taken off PD; whereas an elderly patient whose overall survival is reduced and not suitable for transplantation could remain on PD (Brown et al 2009c). There are also some discrepancies and differences of reported incidence at two and three years on PD. Rigby and Hawley (1998) from Australia, report an incidence of 1.9% at two years which is higher than the Japanese reports of 0.4% at three years (Kawanishi et al 2004); the USA recently reported an incidence of 0.4% at less than six years. Many do comment on these differences, possibly due to case mix differences, diagnostic criteria and methodology used (Johnson et al 2010). The consensus being that up to two years the risk of EPS is less than 1%, but the risk increases thereafter with time on PD, in particular after four years when the risk increases with each year (Rigby and Hawley 1998, Nakamota et al 2002, Kawanishi et al 2004, Johnson et al 2010). There is also agreement that there is likely an increased awareness of EPS, thus the increased publications of incident data over the last 10 years (Wilkie 2010).
However, a number of other factors have to be borne in mind. In the first place, as highlighted in Chapter 1, the average length of time for patients to remain on PD is estimated to be two years, meaning that after two years only 50% will still be on PD (Necosad 2004, Brown et al 2009a). Patients who reach the four-five-year point will be relatively rare. This raises questions about whether discussing the risk of EPS when a patient is starting dialysis treatment is the ideal time. Furthermore, there are many other competing risks that outweigh those posed by EPS, such as cardiovascular disease. It has recently been suggested that a development of a competitive risk score concerning an individual’s likelihood of developing EPS would be more useful, but that this should be:

...balanced in the context of other significant hazards to which they are exposed, and to provide the best advice about whether to continue with PD or consider timely transfer to HD. Clearly the risk is very different for an older patient with significant co-morbidities than for a younger patient without, and is also influenced by other factors such as residual renal function, dialysate exposure, membrane characteristics and suitability for vascular access. (Wilkie 2011).

When the participants in the present study were first diagnosed with CKD they were given no information about the risk of EPS. This is not entirely surprising, because when they first went onto PD, the knowledge of EPS at this time was scarce. However, they also confirmed that they still received no information about EPS after they had been on PD for more than five years, nor when they had meanwhile transferred to HD. This lack of information was perceived as a concern, the fact that most had never heard of EPS or symptoms to be aware of created the problems described in the findings of self interpretation.

The findings of the present study are inconclusive to address when the risks of EPS should be communicated to patients. Participants were directly asked if information about EPS would have been appreciated at the time they were deciding about the choice of modality. The answers were not straightforward, however, and were complicated by the fact that risk information can be difficult to communicate and understand. Communicating risk information is intended to reduce uncertainty, but risk assessment and awareness education can be problematic when the information is
hard to take on board (Brashers 2001). Most participants agreed that if they had been presented with low risk information at the beginning it would not have changed their choice of going onto PD. This became a struggle as they contemplated the consequences of being on PD and it being the cause of EPS. The challenge therefore, is how useful it would be to discuss EPS at that early stage when patients are already faced with major life changes. However, this potentially becomes a practical, ethical and legal issue as withholding information is not something HCP’s should be engaged in and overcoming this issue is both a practice and policy dilemma.

The findings emphasise the need to consider carefully the stage at which EPS should be discussed with patients. The provision of information at the start of dialysis has been discussed in the literature and some insights are offered as to patients needs at that time. Many of the studies of information giving in CKD relate to the decision making process for the choice of dialysis modality, and have examined patients’ roles and their information needs (Breckenridge and Locking-Cusolito 1997, Kelly-Powell 1997, Andrew 2001, Iles-Smith 2005, Tweed and Ceaser 2005, Landreneau and Ward-Smith 2006). These studies highlight the considerable anxieties facing a patient who is required to choose between different dialysis modalities. The decision is mainly based on a broad set of values and beliefs, and is unlikely to be influenced by statistical information (Morton et al 2010). Participants often described a “lack of choice” and absence of information about the outcome of the therapies, but more importantly the decision was governed by a bid to preserve normality (Field 1996, Tweed and Ceaser 2005). The perceived effects on patients’ lives and families has been shown to be of great importance in some studies, but also patients’ wish to understand the long-term effects and to be able to manage their dialysis treatment (Kelly-Powell 1997, Isenberg and Trisolini 2008).

The recent publication of the NICE guidelines (2011) has addressed some of the issues on informed choice and has attempted to dispel some of the myths currently circulating, at the same time providing up-to-date evidence for the factors in adopting a given dialysis modality. Studies examining the impact of education on choice demonstrate that, when provided with good education over a period of time 50% of patients chose home based therapies (Golper 2001, Necosad 2004, Goovaerts et al
2005, Manns et al 2005, Oliver et al 2007). This supports the view that pre-dialysis education should focus on patients’ lifestyles and beliefs in addition to the facts about dialysis. Interestingly, in the studies mentioned above there has been little emphasis on complications, risk factors or prognostic information.

However, prognostic information has been given in medical journals and concerns have been expressed that this information is not normally given to patients (Fine et al 2005, Mendelssohn 2005, Miller 2005, Holley 2007). Much of the argument in the literature concerns the ethical dilemmas and the traditionally paternalistic approach that medicine has adopted. The move to a more autonomous approach, and acceptance of the fact that patients should be fully informed, has advanced the debate, but prognosis is only highlighted in studies of end-of-life care, when patients acknowledge the uncertainty of their prognosis and their demand for more information (Ashby et al 2005, Russ et al 2007). A systematic review of patient information needs by Ormandy has identified as many as 13 topics important to patients. Some of these concerned survival expectations, physical symptoms, body image, lifestyle and other practicalities (Ormandy 2008). Unanswered questions remain, however, on what information is more important to patients at a given time (Ormandy 2008).

There is much to be learned from the cancer literature, where many studies examine prognostic information, the communication of unwelcome news, and patient preferences. A systematic review by Hagerty et al. in 2005 (Hagerty et al 2005) included 274 articles related to the provision of prognostic information, mainly from the USA and Australia. In terms of patient preferences, studies show that most patients want to have prognostic information, although there were some who did not. Most wanted information about life expectancy and the effects of cancer on their lives- but wanted to be asked first. This is supported by studies of patient preferences which demonstrate that asking patients what information they want is important (Degner and Sloan 1992, Caress 1997, Hagerty et al 2005, Holley 2007).

In Hagerty’s review of the literature on prognostic information a large proportion (80%) asked for the information to be qualitative rather than quantitative and given in a directly and honest way. The style of the communication was also reviewed and the
environment, manner, the balance between positive and negative language, and checking understanding were all considered important. Hope is often mentioned, and this is seen to be influenced by physicians’ willingness to answer questions and to provide up to date treatment information and emotional support.

Particular challenges relate to accurate prognostic information being available in the first place (Justice et al 1999, Michel and Moss 2005). It is clear from the incident data presented in table 1 that time on PD is a risk. Other risk factors such as peritonitis, exposure to icodextrin and age have not been accurately or reliably presented in large studies (Wilkie 2011). It has been suggested that a European and worldwide collaboration is essential to provide prospective data collection to try and answer some of these difficult questions, and to provide more accurate prognostic information (Summers 2011).

The present study is limited in the extent to which it can answer the questions of what, when and how much risk information should be given, but the findings do highlight important issues concerning preparation for and transition to HD. In preparing patients to transfer to HD there are a number of factors to be considered. If the move to HD is driven by clinical reasons, including a clinical concern of an increasing risk of EPS, the study reveals some areas of concern.

Participants described their reluctance to transfer to HD, and some of the issues date from lack of understanding at the time they went onto PD as to how long it would last. There was also a general fear and disgust of HD. The focus in the early stages, when patients are presented with the choice of different types of dialysis, should therefore centre on how long the treatment is likely to last, and if they are still on PD at four years’ time, what the risk will be. It is vital to ensure that processes and procedures are in place to allow individual patients to be monitored, and this has been the approach used by NICE (2011). During the current study it became clear that part of the issue with HD was the effect on participants’ autonomy and independence. For those who were able, transfer to home HD enabled them to maintain this autonomy.

There are many different leaflets and other types of information available to patients with CKD and there is currently a national forum to address the range of written
information available. Most of the education and information is targeted at the pre-dialysis stage, informing and educating patients to make decisions regarding their choice of dialysis therapy. EPS at this stage of the illness trajectory is still rare, and the majority of patients are either not at risk or are unlikely to progress to the stage at which the risk becomes significant (Wilkie 2011). How EPS is included in the written information therefore needs to be balanced against information that explains how long PD is likely to last, and information affecting the transition between dialysis therapies.

In the introduction to this study (chapter 1) the reasons for the decline of PD in the UK and other Western societies were discussed. Within the UK, however, there is considerable variation between renal units in the uptake of PD, and this has led to the publication of DH documents (2010), and recently a NICE (2011) guideline, in an attempt to increase PD numbers overall. The NICE (2011) guideline specifically refers to the information given to patients at the time they are making informed decisions on various dialysis therapies, and recommends that potential risks and complications should be covered. How the risk information should be written and presented has yet to be decided. The challenge will be to balance the information about risks associated with PD against the other risks associated with CKD and dialysis. Considerations of age, social factors and patient choice will have to be part of the process in order that patients are not switched unnecessarily from PD to HD or given unbiased information influencing their decisions (NICE 2011).

One way that may assist both patients and HCP’s is to consider recent recommendations of incorporating care planning into the management of individuals with CKD (Mukoro 2011, Seymour 2011). As stated by Lord Darzi it was anticipated that ‘everyone with a long term condition will have a personalised care plan’ (Seymour 2011). The aim therefore is to anticipate the future care and treatment plans required by each individual. If used appropriately these personalised plans may provide opportunities to include risk information and prognosis specific to each individual. A formal written plan may assist HCP’s to address and discuss difficulties such as the risk of EPS.
6.2.2 Early recognition of symptoms, and the problem of “not being heard”

One of the objectives of the study has been to explore the way symptoms were perceived by the participants. The findings have highlighted the difficulties at the pre-diagnostic phase of EPS, including a general lack of recognition of the symptoms and the need to discuss and balance risk information. The perception that the HCPs were ignoring them left the participants uncertain, isolated and at times suffering.

It is however acknowledged that the early signs of EPS can be difficult to detect making diagnosis difficult (Kawaguchi et al 2005, Augustine et al 2009). Two of the participants in the current study had undergone surgical procedures when clear signs of EPS were present but not recognised, again emphasising the rarity and specialised nature of the condition. There have been two key publications aimed at informing and educating HCP’s (Brown et al 2009b, Renal Association 2009). One of these has appeared in an international PD journal, and the other is a publication issued by the UK Renal Association. Both were published during the data collection period of the present study and their impact on HCPs cannot yet be assessed.

The early symptoms were usually interpreted by the participants themselves as not being significant, and symptoms were associated with unrelated causes. This maybe in part due to lack of information being made available to them. When a patient on PD has reached the stage where the risk of EPS is becoming significant, providing them with written information and verbal discussion of symptoms would help to prepare them for potential difficulties likely to cause pain and discomfort as described in the findings. At the time of this study no written information was available in the centre where the study was undertaken. The one other specialist centre does in fact provide a brief leaflet given to patients at time of diagnosis, describing the surgery and some expectations. This does not address the issue of information at the time of transition to HD.

Some of the symptoms described by the participants have been highlighted retrospectively by dieticians in the centre where EPS surgery is performed (Jordan et al 2007). The symptoms therefore are in fact recognised and documented (Kawaguchi et al 2005, De Freitas et al 2008, Brown et al 2009b). Translating this into practice as a
way of both informing patients and HCP’s, although challenging needs to be considered for future clinical practice.

Literature on self-management often makes reference to being bodily aware and the need to monitor symptoms. The participants in the present study had experience of home dialysis and self-management. Self-management is now recognised to be an important component in the ability of patients to live and cope with a long-term condition (Thorne et al 2000, Koch et al 2004, Kralik et al 2004). Wilde and Garvin (2007) have provided a concept analysis of self-monitoring, suggesting that it has two attributes:

*Awareness of bodily symptoms, sensations, daily activities and cognitive processes, and secondly, measurements, recordings and observations that inform cognition or provide information for independent action or consultation with providers* (Wilde and Garvin 2007).

All the participants in the study were familiar with self-monitoring, indeed monitoring and recording is integral to self-care dialysis and even HD as a whole. Some participants on in-centre HD the active self-monitoring and control of their treatment had been taken out of their hands by nurses and doctors.

The cognitive processes of how participants perceived their symptoms can be interpreted with reference to the ‘body listening’ and ‘bodily awareness’ described by Price (1993). Becoming attuned to bodily symptoms, and the difficulty in distinguishing between the symptoms they can manage themselves and those that need to be reported without delay, has been described in other studies (Kutner 1987, Curtin et al 2004, Giles 2005). This is an important controlling aspect of illness and has certainly been detected in the present study. In the current study participants reflected on an array of symptoms they initially chose to ignore, finding their own reasons why they were occurring. As experts in their own self-management this is a common attribute (Thorne et al 2003), and it was only when the symptoms persisted and they became aware of their own deterioration that they began to report them. Sometimes it was even their families that persuaded them to acknowledge the symptoms and seek help. Although they were themselves aware that there was an underlying problem, the
healthcare teams did not seem to know the cause of the symptoms reported – or if they did, it was not effectively communicated to the participants. Healthcare relationships are a fundamental and important aspect of CKD. The trust of the participants in the HCPs had essentially been missing until they were given the diagnosis.

Comparisons can be drawn with the broader literature, particularly regarding the issue of “not being heard” by HCPs. Many studies have concentrated specifically on conditions that are difficult to diagnose, such as SLE, fibromyalgia and rheumatoid arthritis (Brown 1995, Kralik et al 2001, Weiner 2004, Madden and Sim 2006, Nettleton 2006, Stockl 2007). These studies emphasise that patients need to legitimise their symptoms by being given a label, when the diagnosis then becomes more meaningful.

In the current study, some of the interviews brought out this feature and one could almost hear the relief in the participants’ voices as they recounted the time they first met the surgeon and were actually given a diagnosis and a name for their condition – and their concerns were thus legitimised.

Other studies describe problems within healthcare relationships on the basis of patients not being heard, or even being misdiagnosed. The power imbalance in the relationship and the traditionally paternalistic approach of HCPs are often mentioned (Kralik et al 2001, Madden and Sim 2006). The issues of medical dominance in cases of unknown or uncertain diagnosis have been described in the medical and sociological literature (Fox 1980, Adamson 1997, Crawford 2004, Nettleton 2006, Stockl 2007). The effect of rapidly advancing technology, ever-changing scientific research and the continuous strain of not being able to live with uncertainty are also mentioned (Adamson 1997). In the case of EPS, the present inability of scientific research to answer its uncertainties remains a dominant problem for the medical profession (Augustine et al 2009).

In the current study, the participants found themselves in a difficult situation due to the very complexities of their illness; this is then compounded by the lack of knowledge of EPS and the resulting absence of guidance. Most reporting of the symptoms of EPS takes place in the HD units, but the data suggests that HD nurses and doctors are not sufficiently aware of this relatively rare condition. Patients on HD also
have access to other members of the MDT such as the dietician who can often play an important role in nutritional management. The Renal Association (2010) standard for nutrition in CKD, states that all stable patients on HD should be reviewed by a renal dietician every three-four months. Measurements specific for signs of malnutrition such as the subjective global assessment (SGA) are recommended. Other tools such as the malnutrition universal screening tool (MUST) can also be used. The use of these tools should be able to signal early symptoms of EPS reported by the participants in the study, although additional information of more general gastro intestinal symptoms would be useful. Implementing and monitoring Renal Association standards however is very much up to individual units. The provision of specialist renal dieticians is dependent on local services and their own costs. One consideration for clinical practice would be to incorporate specific nutritional assessments applicable to patients who have been on PD for more than four years. This can be added into the Renal Association standards (2010) and included in dietetic literature aimed at renal specialist dieticians.

The importance of paying greater attention to how EPS is described still needs to be emphasised. Even if this means that HCPs may not always be confident about a definite diagnosis, acknowledging this uncertainty and supporting the patient are vital. During the current study participants had on occasion been aware that the HCPs did in fact know what was causing their symptoms, but they chose not to say anything. As Nettleton (2006) has pointed out in a study of medically unexplained symptoms for which no diagnosis is known, a simple acknowledgement can serve to avoid the patient feeling a “fake”. In Nettleton’s (2006) study, participants described being told at times that the problem was merely due to “anxiety”, which is described as a threat to their sense of self and social identity. A study by Thorne (2000) also identified some of these issues in patients with long-term conditions finding health care providers controlling information and ‘clinging’ to their role as experts. There was little appreciation of patients’ own theories or understandings that maybe contributing to their illness (Thorne et al 2000).

Much of the sociological literature is quite specific about the medical encounter (E.g. Bury 1982, 2004), but there is little mention or discussion of nursing in this context. It
is interesting that during the current study the participants identified both medical and nursing staff as being part of the problem, in that both groups neither recognised nor even acknowledged their symptoms. This is probably a reflection of the nature of CKD and the fact that most patients on dialysis have more contact with the nursing staff than the doctor. Some of these issues can be related to work by Bevan (1998), who describes the work of dialysis nurses and the environment. In particular he suggests the notion of “enframed” nursing, in which the focus on technology and biomedical parameters exceeds the caring aspects (Bevan 1998).

In the literature review (Chapter 2) relationships with HCPs were frequently referred to and for those on hospital HD this was often a negative factor. The medical discourse was reported as overpowering bodily sensations, and an asymmetrical relationship therefore existed between the patient and HCPs, in which the patient’s voice may not be heard (Faber et al. 2003, Giles 2005, Kierans and Maynooth 2001, Polaschek 2007, Velez and Ramasco 2006). From the findings of the present study it seems that being ignored while on dialysis may be an example of this. A qualitative study by Moran et al (2009) of patients on haemodialysis reported nurses rarely communicated with them, they were only approached to manage technical and physical aspects of their care (Moran et al 2009a). When people feel dismissed during contact with HCPs they feel diminished and unsupported (Telford et al 2006). This is supported by the current study when participants reported feeling ‘unheard’ and ‘ignored’, whilst they continued to suffer with progressively worsening symptoms. The relationship with the surgeon was often a turning point as they had been given a diagnosis; they immediately felt trust and actively engaged in preparing for the surgery. Seeking information at this point was often an issue and many individuals with EPS were dependent on the internet, or on asking other HCPs. By the time of the second interview they were asking a number of questions, as they sought to understand the causes and long-term effects of EPS.

In a study by Curtin and Mapes (2001) of long-term survivors on dialysis, much of the self-management observed was related to how they managed the relationship with the HCP’S. Actively suggesting a treatment, or even declining treatment, may entail a confrontation with healthcare providers (Curtin and Mapes 2001). In the current study
some participants who had a strong background of self-management struggled with their symptoms of EPS. Not being armed with information left them powerless in the healthcare relationship and created the uncertainty described in the findings. As suggested earlier, if they had known the significance of their symptoms this would have influenced how they reported them, reducing their reliance on the HCPs who they often perceived to be lacking knowledge.

Lack of knowledge is an issue related to practice, and informing patients of the risks of EPS remains a major challenge to healthcare teams. The relative rarity of the disease and the fact that the risk increases with time on PD are factors to be considered. From the current study it is very clear that the provision of information needs to be addressed. At what stage in the illness trajectory EPS is discussed may be answered using the competitive risk tool suggested by Wilkie (2011), in which all the risk information is discussed with patients before they embark on dialysis treatment. It may however be some time before this is available in general clinical practice. An area that could immediately be rectified is the provision of written information for patients at the time EPS is diagnosed. Patients still on PD after four years require their risk factor status to be assessed, taking into account their age and other co-morbidities and informing them of the potential signs and symptoms of EPS (Brown et al. 2009b). Outlining the ways the symptoms will be monitored and the symptom profile to be expected can become part of the process.

Educating the wider teams, especially in HD units, is also an area that requires attention to ensure that HCPs gain confidence in diagnosing EPS at an early stage. This will have the effect of avoiding acute admissions and ensuring early referral to a specialist centre for surgery. This is not necessarily a straight forward issue of educating and informing, since as already discussed there appears to be cultural and practical issues with communication between HCP’s and patients within a HD unit. The impact of newer guidelines (Brown et al 2009b, Renal Association 2009, Nice 2011) has yet to be realised, but should provide HCP’s with additional knowledge and understanding of EPS.
6.3 Embodiment – The impact of surgery

A major part of the impact of EPS is related to the surgery. The experience of EPS was seen as a “bodily experience”, encompassing the onset of symptoms, body changes and appearance, the major surgery endured, and ongoing recovery.

Describing the experience as “embodied” is a feature of the philosophy of Merleau-Ponty (Wilde 1999). This involves a shift away from viewing the body as a total physical entity separate from the mind. This is relevant to the participants’ view of their bodies, not necessarily as a separate objective entity but as an integral part of the experience. As Wilde (1999) points out, an assumption of embodiment is that all parts of the body are integral to the human being; no part can be separated from the rest or be objectified. So, as persons are said to exist through their bodies, the body constitutes their presence in the world and cannot be separated from the self (Lindahl et al 2007).

In long-term condition, or at other times of bodily disruption, this is no longer the case and the body is seen to be dysfunctional and even alien, and there may be a feeling of betrayal by the body (Williams 1996). From this comes what is described as “disembodiment”, when the body is regarded as separate from the self.

In this current study the participants described many aspects of the embodied experience and of disembodiment. CKD, and particularly dialysis, can create issues of body image and bodily disruption. These may be focused either on a fistula or line in HD or the catheter in PD (Muringai et al 2008). There are however relatively few references in the literature to how the embodied experience relates to these technologies or appliances and how they are perceived; as Wilde (1999) has pointed out, we cannot assume that people can separate themselves from these technologies. Some studies refer to body image, as identified in the literature review. In particular, stigma and disgust may be directed at either dialysis catheters or the scars from surgery (Lindqvist et al 2000, Kierans and Maynooth 2001, Curtin et al 2004). One participant in the current study specifically referred to her PD catheter and its influence on her body image, and described how she eventually learned to accept and live with it. This supports Curtin’s (2002) study of long-term PD patients, in which they
came to terms with the PD catheter and could then move on. However, other references to body image, specific to EPS, have arisen during the current study, for example changes in outward appearance, weight loss, eating habits and the scars remaining after surgery.

The other important aspect of embodiment in the present study relates to enduring the surgery and the effect on patients’ bodies of the suffering and pain, changes in body appearance, feelings of alienation and the stoma formation. Each of these will be discussed separately.

Participants in the current study were aware of the risk of stoma formation and expressed anxiety. Of the three participants who had had stomas, however, the one participant in which it was permanent seemed to have accepted it and was managing it well himself. Unfortunately the other two experienced disgust and feelings of alienation when they discovered the stoma. In the literature on EPS surgery there is little or no mention of the impact on the patient’s quality of life or the after effects of the surgery, such as stoma formation. According to what patients have been told, stoma formation can occur in 15-20% of cases. In Japan one study reported less than 10% chance of a stoma (Kawanishi et al 2005). It is often not clear until the time of the operation whether a stoma will be necessary. Another study from Japan has reported an increase in depression following a stoma, although no details are given as to how this was measured, and recommended psychological support for patients following EPS surgery (Nakamoto et al 2002).

Literature describing patient experiences of stoma following colorectal surgery have similarly commented on some of these issues. In earlier work by Kelly (1992) he describes “self” and “identity” following radical colorectal surgery, and the awareness of the changed body through the pain and shock to the disrupted private self. Some individuals do however cope positively:

*The awareness of difference, in other words, is linked to awareness of survival, and the changed body is the price of the survival of self* (Kelly 1992).

For the one participant in the current study who had accepted the stoma, this may have been a reflection of his view of feeling lucky to have survived. The other two
participants, both women, felt alienation towards the stoma and were greatly traumatised, echoing the conclusions of a study by Notter and Burnard (2006) of women’s experiences of loop ileostomy surgery. They emphasised the importance of preparation and post-operative pain management (Notter and Burnard 2006). Psychological preparation before stoma surgery is also important (Noone 2010). Due to the complexities of the surgery and its unknown effect, the participants in the present study received no psychological preparation from stoma care nurses before the post-operative period. This has since been addressed in the centre where the study was undertaken, now all EPS patients are seen by the stoma nurse specialist prior to surgery. A synthesis review by Thorpe et al. (2009) of bodily changes following faecal stoma formation presents three major themes from the studies, much of which can be related to the current study in the way embodiment is reported. In their review, loss of embodied wholeness is related to a negative focus on the body, and to the alienation and objectification of the body. Awareness of the disrupted body occurs when the disruption is forced into the consciousness. For the participants in the present study this was not only related to the stoma, but also to the major surgery they underwent and the constant disruptions it caused.

The final theme Thorpe et al (2009) describe is ‘disrupted bodily confidence’, where there is seen to be a separation between the body and the self. This has been described by Gadow (1980) as “disrupted immediacy”, in which the self and the “objective body” become separated. The way in which an individual can negotiate through this can be a struggle, although some authors see it as a normal transition (Morse and Mitcham 1988, Williams 1996, Wilde and Garvin 2007). Gadow (1980) describes transcending to a “cultivated immediacy” in which the body and self are reunited (Gadow 1980). Gadow argues that this new situation is unlike the disrupted bodily experience, in which the body and self are unnoticed, and now the body and self are distinct but are not opposed (Gadow 1980). For the participants in the study this can be used to explain the new body, how they negotiated new ways of eating, and the stoma and the scars left by the surgery.

There are also other important aspects of the experience of EPS that need attention from the perspective of embodiment. The pain some of the participants described
before and after the surgery is another way in which the body becomes an object of alienation. As Williams (1996) argues, loss of confidence in the body is quickly followed by loss of confidence in the self. For these participants the loss of confidence in the self was compounded by loss of confidence in the HCPs, leading to the point of being desperate for relief from suffering. The suffering, desperation and pain became a process of endurance. The amount of pain described by the participants is important, the ward where the surgery takes place has access to pain control teams and regularly uses self regulatory pumps. Effective pain management is supposedly a routine part of the post-operative surgical care (Noone 2010). As part of the patient assessment pain is monitored each time an observation is undertaken. The findings from the study therefore need to be reported appropriately to consider how effective pain management is monitored in the EPS cases, as their needs seem quite specific and according to these participants are often not being met.

Suffering is described many times in the findings and is alluded to in a number of qualitative studies in which the meaning or experience of illness is examined (Strandmark 2005). Suffering is a term often associated with physical pain, and in the modern view a patients’ suffering is regarded as negative or “bad” and something that needs to be eliminated (Carnevale 2009). However, Carnevale (2009) discusses suffering from an ethical and moral standpoint, and concludes that it cannot be objectively understood or observed externally, but is akin to an emotion and can only be experienced subjectively. This view is shared by Frank, who depicts suffering as the essence of an illness that is “unspeakable” or concealed (Frank 2001).

Charmaz (1999) describes accounts of suffering in long term condition in relation to the self and the moral context; she argues that when suffering is legitimised then moral rights and entitlements can elevate a person’s moral status. This is different from the view of Carnevale (2009), described above, as it has a more positive connotation. Charmaz (1999) takes the concept of suffering beyond one of emotion and physical pain and introduces control and uncertainty as factors that affect the self. In this sense, suffering gives rise to actions as well as feelings. In a long-term condition, suffering is often present in the background and can be insidious; it is a feature of the self and is a social factor (Charmaz 1999). There is also frequently a moral issue aligned
to suffering, which Charmaz (1999) describes as a “hierarchy”, and often comes at a
time of crisis or following a near-death experience. Its status changes over time,
however, and a person can then find himself in the position of being “worthless”. It is
not always clear how patients portray this to others. The moral status of suffering is
not always articulated and those that display anger may well be attempting to protect
their moral status (Charmaz 1999).

In the present study the crisis was very closely linked to the near-death experience,
and the despair and feeling worthless occurred when participants could endure no
further suffering. Other studies of long term conditions have generated similar themes
in relation to suffering (Ohman et al 2003, Strandmark 2005), and in the literature
review for the present study suffering was referred to in studies concerned with
experiences of dialysis, relating to the physical and emotional stresses involved.

Hutchinson (2005) suggests that a lack of understanding can make suffering worse,
due to inappropriate medical intervention or a lack of belief by HCP’s in the individuals
who are undergoing the suffering. He uses the palliative care model to address
suffering in renal failure and the lessons that can be learned from a holistic approach
(Hutchinson 2005). In the current study, suffering was not necessarily the description
used by the participants, although one of them vividly described the months of
suffering before she received a diagnosis.

As mentioned earlier, the endurance described in this study relates to the ongoing
bodily experiences and the total despair experienced by some participants. In work by
Dewar and Morse (1995) with patients who have undergone illness, injuries and
traumatic events, they describe a failure to endure (Dewar and Morse 1995):

THE UNENDING ASSAULTS TO PHYSICAL SELF AND FREQUENT THREATS TO PSYCHOLOGICAL
INTEGRITY BRING THE INDIVIDUAL TO THE LIMITS OF ENDURANCE.

Endurance is related to behaviour such as anger and may indicate a person’s inability
to endure, or being determined to retain control so as not to expose the emotional
turmoil they may feel. In further work by Morse and Penrod (1999) they define the
concepts of hope, enduring, uncertainty and suffering as processes that an individual
may go through, not always in a linear manner but back and forth. Enduring can
involve holding on in reaction to an extraordinary threat (enduring to survive), a psychological shutdown in response to a psychological threat (enduring to live) or wanting to give up and end it all (enduring to die) (Morse and Penrod 1999). In endurance, emotions may be suppressed, in which case the priority is just to get through, and this can certainly be related to the endurance shown by the participants in the current study. The moments of despair described in the findings, and the fact that two participants wanted to give up altogether, illustrate the psychological threat.

Being able to understand the emotional response to the threats the participants endured and the suffering they went through is valuable in improving communication and in nursing patients through such a difficult time. For HCPs to observe emotional responses such as anger and frustration is also important. These reflect the threats described and the suffering patients may have to endure.

At a recent meeting hosted in Manchester (July 2011) by the two specialist centres, surgeons discussed the increase of open abdominal techniques in EPS surgery. They indicated the potential for improved outcomes by leaving more patients with open abdominal wounds post-operatively. This again has implications for the care, management and psychological needs of patients. The information and psychological preparation for these patients will require input from the wider specialist teams. The fact that only two centres in the UK offer surgery enables communicating and sharing practice easier. The two centres meet once a year to discuss the issues of care, management and outcomes. Influencing changes to practice and sharing research is therefore focused and productive. Sharing the experiences expressed by the participants in this study and communicating the findings with HCP’s who care for and manage patients during and after surgery is an achievable goal. Both centres now have EPS co-ordinators who are responsible for arranging transfer and organising surgical dates for patients with EPS. They may be able to influence some of the issues raised in this current study.
6.4 Transitions – Views of PD

As part of their reflection and description of the EPS experience the participants described the transition from PD to HD. This was a particularly interesting finding and has highlighted some important and relevant aspects of care.

When discussing the move to HD, issues of control and independence came to the fore. HD imposed more restrictions; participants felt less in control and lost some of the independence they had become accustomed to on PD. They even recounted their attitude towards HD before the transfer, and having resisted it as long as possible. This was expressed remarkably strongly, using terms such as fear, and in some cases even ‘loathing’.

Since long-term PD is a risk factor for EPS, this is an important aspect of patient management and care. It is essential that patients are given adequate information and preparation ahead of the transfer to HD. The transitions between dialysis therapies is well documented in the literature in terms of the integrated care concept (Davies et al 2001), and recognises the probability that patients with CKD will at some stage go through a range of dialysis modalities (Fluck 2008, Murtagh 2008). These issues have rarely been studied from the patient’s perspective (Hutchinson 2005), and the present study is able to offer some insight into the difficulties and challenges that are likely to face clinicians in preparing patients for the transfer.

Patients tend to perceive their time on PD as a period when they were well, had more freedom, were well adapted and integrated, and in many cases had been able to continue to work. Studies examining the reasons why patients choose PD therapy often demonstrate how important these factors are (Morton et al 2010), more important even than outcomes and the survival statistics. Having a sense of control over their treatment, their lives and their freedom can be described as empowerment, a view also found in Curtin et al’s (2005) study of self care strategies in PD patients. This study also emphasised the importance of achieving normality particular in PD as the treatment offered such flexibility (Curtin et al 2005).

The recent NICE guidelines (2011) describe the initial process of access to information and the support required for individuals to make informed decisions about their choice
of dialysis modality. They also include guidance as to how individuals should be prepared for lifelong treatment and how a switch to an alternative therapy may eventually be necessary. Being given a realistic view of PD as a therapy that is unlikely to continue much beyond three years is part of that process. Ensuring a regular review and preparing patients for the switch is important. For some participants in the current study, transferring to home HD was in fact a way for them to regain some of the independence and freedom they had associated with PD. Recognising when PD is failing is crucial and forms the basis of planning the transition, including formation of a fistula (Chiarelli et al 2008). There are those cases where the switch is an emergency, as in the case of peritonitis and so planning cannot be done. That does not mean patients cannot be informed of the potential complication and the need to transfer.

6.5 EPS – A Challenge within a Long-Term Condition

The aims of this study were to explore the experience of EPS in the context of the participants ‘life journey’ with CKD and to explore the meaning of EPS. For the participants in the current study, the life world of their long-term condition has played a major role and, having adjusted to living with a long term condition, they had already developed views as to how this had been achieved. In other words they had experienced losses, changes to life and to ‘self’ and ‘self identity’ as described by others (Conrad 1987, Charmaz 1997, Morse 1997). The findings of this study have highlighted many aspects of adjustments which concur with those identified in the literature review (Chapter 2). This is also reflected in the broader literature of adjustment and adaptation in long-term conditions (Lazarus and Folkman 1984, Paterson et al 2001, Sharpe and Curran 2006, Telford et al 2006, Samson and Siam 2008, Larsen and Hummel 2009). Sharpe and Curran (2006) describe common features of all the models, suggesting that when individuals face a health crisis they develop representations of the illness that are influenced by their pre-existing belief structures. Adjustment is then the process of maintaining a positive view of the self and the world in the face of a health problem (Sharpe and Curran 2006). The relevant findings of the
current study can be related to an acute event, in this case EPS. More pertinent to this study is what is described by Curtin et al. (2002) who examined the processes determining the patient’s ability to survive on dialysis. Curtin et al. (2002) discusses the transformation of patients and how they have accomplished this, not necessarily passively but often actively, in their endeavour to reconstruct the “self” to embody self-identity, self-worth and self-efficacy. In particular, there is interest in the process of setbacks described as “risk of death” and “repeated setbacks”. These views seem relevant to the current study, as the participants experienced adjustment to CKD and dialysis, achieving a balance of normality until EPS again brought the illness into the foreground, accompanied by an unexpected degree of suffering and trauma. This is also closely related to a model developed from a meta-synthesis of long term condition studies by Paterson (2002):

*The Shifting Perspective Model shows living with chronic illness as an ongoing, continually shifting process in which people experience a complex dialectic between themselves and their ‘world’.*

The model described starts with illness in the foreground and is characterised by focus on the fact that suffering during sickness is destructive both to the self and to other people. The shift in perspective discussed is one of “wellness in the foreground”. The individual then makes the self the identity, not the disease. This shift in perspective is not linear and can change when there are threats to self or during times of acute events. This theory sits well with how participants in this study described the impact of EPS, renegotiating and redefining their roles, losses and everyday living was part of the process. The empowerment participants strove for was related to their own belief in their ability to manage their long term condition – not merely the day to day regime, but also making the decisions and managing the symptoms; a feature found in other studies of long-term conditions (Thorne et al 2002, Thorne et al 2003, Kralik et al 2004). Managing EPS as part of their life journey was part of these aspects described.

The present study was intended to focus on the meaning of participants’ experiences based on in-depth interviews (Lindseth and Norberg 2004), the findings however demonstrated that participants views were about ‘finding life meaningful’. This concept of meaning is similar to that described by Lee and Poole (2005), who used a
transactional model to show how meaning was derived in people with long-term conditions. They described meaning as a cognitive process and meaning was one aspect of an individual’s coping repertoire; nevertheless finding benefits from the experience was important in creating a sense of meaning against all the struggles (Lee and Poole 2005). From an existential view, the participants in the current study had endured the crisis and trauma of EPS, and against the odds had survived. Since it was associated with their long term condition, they had already overcome some of the insecurity of their own existence. Since EPS was perceived to be more serious, they saw themselves as being lucky, and each new day was a bonus. The appreciation of life and taking positives from the experience was part of that process. Although death might seem an opposing view of taking a positive view of life, for these participants their acceptance of death as a possibility was used in a positive way.

The adjustment and acceptance of the possibility of dying can be related to Heidegger’s description of authentic and inauthentic self (Guillickson 1993). The authentic self is aware of the significance of ‘being’ which is that we are all ‘being’ toward death. The inauthentic self views death as an actual event i.e. would happen to another and is an object to be feared (Guillickson 1993). In Guillickson’s (1993) study of long term conditions those participants who viewed death as a possibility and reappraised their life as feeling lucky were describing the authentic self. Certainly for participants in this current study, the authentic self for those that now viewed life differently was an important moment in authenticity as they were aware of not being in death.

The personal attributes described in the findings of this study have been used in other studies, not of just CKD, but of other long-term conditions (Larsen and Hummel 2009). These were focused on remaining positive, resilient, determined and optimistic (White and Greyner 1999, Curtin et al 2004, Mitchell et al 2009). These attributes have created some interest in the literature, in particular how they contribute to outcomes and survival in certain conditions. Much of this work is reported in the cancer literature. Studies by Taylor et al. (2000) of women with breast cancer have identified optimism as being related to a sense of control and the ability to find meaning in one’s life. These are described as positive illusions that can have a protective psychological
effect, especially in the context of severe life-threatening events (Taylor et al 2000). Further work has also been developed in different populations to study the effect over time of positive attitudes towards HIV and cancer on physical health (Taylor et al 2000).

King’s (2002) study of adaptation to renal disease and diabetes found that stoicism was a dominant strategy, but was also a representation of how one presents oneself to the world. King proposes that stoicism (with a strong fatalistic tinge) helps to overcome uncertainty and is the only constructive alternative to depression and despair (King et al 2002). In the current study the participants certainly experienced periods of despair and intense suffering, even depression. How they portrayed stoicism was perhaps when they described the way they had “got on with life”, not allowing EPS or dialysis to dominate it.

A recent review of positive thinking for cancer patients by Tod et al. (2011) has highlighted the lack of effect shown by positive thinking on outcomes and survival, and also that although positive thinking is a useful strategy there is some danger in not allowing patients to express negative views (Tod et al 2011). The emphasis on optimistic views and positive thinking has been applied to CKD populations, and Christensen (2002) has examined the link between personality traits and mortality in CKD. His study used well-validated measures of personality traits and was able to demonstrate increased mortality in those with low conscientiousness and high neuroticism (Christensen et al 2002). Neuroticism is linked to high levels of psychological distress and is associated with poor adjustment to illness; conscientiousness on the other hand reflects a high degree of self-control and self-discipline, likely to be associated with independence and the ability for self-care (Christensen et al 2002).

In the current study it seems that optimism was employed by participants and seemed to be an effective defence against the negative effects of EPS. The ability of participants to carry out PD independently for long periods suggests a high degree of conscientiousness. The attributes described relate to how well they have coped with the trauma of EPS, and through this how they have found new meaning. This is demonstrated by how they felt lucky to have survived and therefore viewed life differently. Finding meaning after such traumatic occurrences has been reported in a
number of studies associated with trauma or life-changing events (Janoff-Bulman and Frantz 1997, Fjelland et al 2008). These authors point out that to attribute meaning to an event two important questions must be answered, firstly whether something makes sense and fits into a system of accepted rules or theories, and secondly whether something has value or worth. Along with these come questions about the world in general versus one’s own life in particular (Janoff-Bulman and Frantz 1997). The idea of “what really matters” gives survivors a new sense of existence. As Janoff-Bulma (1997) points out, survivors see beyond the biological basis of “being” to the more symbolic aspects of “existence”.

6.6 Support structures

Support given to the participants in this study came predominantly from their families, who themselves will have gone through periods of stress and anxiety. The families of the participants had been involved to varying degrees in their dialysis care at home. On the other hand, some participants had managed dialysis on their own in order to shield members of the family, especially children, from intrusion into their lives; all of them displayed strong emotion when their families came into the discussion. As well as helping them through the whole experience, families provided the focus of something to live for.

Participants in the current study said they could not have got through the experience of EPS without the support of their family. Providing support for families is therefore an essential element of the care required. How this is achieved is one of the challenges for the health care teams to address. The study highlighted the participants’ perspective of the impact on the family, and although the study did not set out to include families/carers, two family members contributed to the interviews and clearly demonstrated the anxiety and stress EPS had caused for them as well as for the patient.

Current policy does recognise the role of carers in patients with long term conditions (DH 1999, DH 2010b) but the more recent DH (2010) carers strategy document has yet to be implemented. However it has highlighted many issues for carers, recognising their views on lack of information available, exclusion from HCP interactions and many other aspects relating to the social and psychological aspects of their roles as carers. Renal patient carers can also access information via local kidney patients associations and the National Kidney Federation (NKF). These however give general information and advice, and they do not have specific information available for EPS, but would act as a resource for carers to make contact. It is also important for HCP’s to acknowledge the difficulties families maybe going through, and in the present study reference was made to families even being involved in the day to day care needs on the ward. One positive aspect of the EPS co-ordinators role is to provide a point of contact for patients and families. This allows the families access to someone who understands and acknowledges the traumatic and difficult surgery their family member is undergoing.

The financial and emotional implications for some of the participants’ families of the distance to the hospital also need to be addressed. Providing adequate accommodation and reimbursement would have financial implications for the providers of the service and was not included in the original funding set up for EPS surgery through NSCAG. Overcoming these issues may need further attention. Referral to social workers may help some families with the financial burden but it is something that requires careful consideration. It is not uncommon for patients to be referred from other countries, in which case the implications of language barriers and family constraints also need to be considered.
Some participants describe the support they have derived from spiritual sources. For them their spiritual faith and beliefs have provided comfort and help during the difficult times they have endured. Two of the studies identified in the literature review (chapter 2) describe spirituality as a strong coping mechanism, and the influence it can have over an individual’s ability to deal with stress and negative events must be acknowledged (Walton 2002, Tanyi and Werner 2008). Patients in hospital have the use of the hospital chaplaincy, and one participant described a support group from within her own religious community. The sustained support they provided gave her comfort and relief, something nursing staff may not always be able to offer. Spirituality and religious beliefs are often quoted as essential components of coping with CKD (Weil 2000, Kelly 2004, De Guzman et al. 2009).

Access to social workers, counsellors and psychologists has become a part of the multidisciplinary approach applied to renal services. These developments have recognised the social and psychological impact of CKD and have identified the type of support individuals require as described in the background of this study. Social support is seen as an essential component of managing long term conditions and some would argue influential on patients’ outcomes (Anderson 1996, Lee and Poole 2005). A study by Davison et al. (2010) specifically examined supportive care needs of patients on all types of dialysis, demonstrating more than 50% wanted help with worries, finding hope, relaxation and stress management and finding meaning. The study emphasised the need to address suffering, meaning and hope (Davison and Jhangri 2010).

EPS has an even greater impact and individuals may need further access to support networks. The renal counsellor and psychologist employed by the unit where the study was undertaken have become involved in the patients admitted for EPS. Much of this support relies on referrals by nursing and medical staff. There is perhaps a need to consider the longer term psychological impact of EPS and ensuring that patients can access these types of services when returning to units in their own geographical locality.

One aspect of support that has also been a focus for the DH is through peer support groups. The development of the expert patient program(DH 2001) has been designed to enable patients to learn and be supported by other patients, but the primary focus
is on self management. The Kidney Patients Association and the NKF provide support to patients as peers, and a study by Hughes (2009) demonstrated a very positive response of utilising peer support in making decisions in CKD (Hughes et al 2009). An area that needs to be explored is how peer support could benefit patients with EPS. Two participants in the current study have offered to speak to other patients who have been diagnosed, in fact one has recently written his own experience into a diary that he wishes to be available to other patients.

6.7 Putting the Findings into Context

This study was essentially based on the experiences of patients with a long-term condition and the life changing acute event of EPS. Comparisons have been made within the discussion of other long-term conditions, particularly in communication and information gaps when patients often find themselves managing symptoms with no explanation or understanding from HCP’S. It is true to say that many other long-term conditions have ‘acute’ events of even exacerbations of the condition, and also complications from particular treatments. This is often the case in cancer when powerful and potent drug and radio therapy regimes cause horrendous complications (Paulsen et al 1996, Newell et al 2004), with late effects of treatments that impact on quality of life and may require further surgery (Sanna et al 2007, Ganz et al 2009), similar to those participants in this study. Another aspect that resonates with this study is that in some cancers risks of complications can be difficult to predict (Lamont and Christakis 2003), and information needs are not being met with regard prognostic information (Hagerty et al 2005).

Patient information, shared decision making and informed consent form part of the process of the preparation for such treatments. The findings of this study highlight information gaps even when the risks of such complications maybe low and the need for HCP’s to be vigilant in surveying for such complications. More importantly involving patients in discussions of the risks resonates across a wide range of long term conditions and would prevent the uncertainty and suffering found in the participants of this study.
6.8 Strengths and Limitations

Discussion of the strengths and limitations of this study will also incorporate issues of reflexivity and quality, as outlined in Chapter 4.

As a means of investigating patients’ understanding and lived experiences of EPS, the study was limited to exploring the perceptions of patients. However, the method used does not have to be restricted to interviews. To add depth it might have been useful to observe some of the interactions and experiences within the ward in which patients were cared for after EPS surgery. This would have allowed some of the complex procedures that had such an obvious impact to be observed from a research perspective.

Munhall (2011) advocates using multiple sources in phenomenological investigations to try to understand the phenomena involved, but this is mainly a feature of the descriptive approaches associated with Husserl (1913). It might also have been beneficial to include HCPs’ perspective on the difficulties encountered in trying to diagnose EPS. However, this would have changed the studies dimensions and the methods employed. Furthermore, a counter-argument to this is that the patient perspective on EPS has never before been explored; hence it was the most appropriate focus for the current work.

The rarity of the condition has tended to restrict the recruitment of participants, although the small numbers in the study are not necessarily a limitation. The possibility of a second interview after a few months to assess the impact of surgery was a definite advantage, but the study was not able to show the longer term impact of EPS, say after one or two years. A follow-up after two years would reveal whether and how the individuals had adjusted, particularly whether they had been able to recover their pre-EPS state of health. Three of the participants in the study have since died, although only in one case was death directly related to the recurrence of EPS. I am still in contact with two of the other participants as they are under the care of the hospital I work in – indeed one of these has recently written a personal reflection of the whole experience which he hopes may help others following. The age range of the
participants was narrow, a result of the small sample but also a reflection of their CKD illness and history. They do not represent the average CKD population in the UK, which is over 65 years of age (Renal Association 2009) but are representative of patients likely to have EPS (Habib et al 2010, Johnson et al 2010).

In this type of qualitative inquiry and hermeneutics, my own role as researcher may not only have influenced the interviews but also the interpretation. Bringing my personal experience into the interviews will have shaped the way the questions were framed. My own preconceptions and bias will have therefore influenced the way the interviews evolved. Being a co-participant as a researcher has both advantages and disadvantages. My own experience and knowledge of the subject could be strength, since the participants were experienced patients with a rare and complex disease – indeed Gadamer (1975) considers this an essential requirement. On the other hand another researcher from a different background might have conducted the interviews differently and reached different interpretations. This was acknowledged during the study, but the discussion provides the critical framework for the ways in which the interpretations might be used to guide future practice.

A potential area of conflict, previously described as reciprocity, was my role as clinician (Carolan 2002). I was aware I had talked and contributed during the interviews and when I listened to the recordings this was apparent. During the second interviews in particular, the participants asked lots of questions and I felt I had to answer these as best I could. This became part of the shared understanding, but it emphasised the lack of knowledge surrounding EPS and how patients were had unanswered questions.

Another limitation of this study was related to the methodology itself. Phenomenology and hermeneutics can be difficult for a novice in the area to understand. As an experienced clinician I had no anxiety about the interviews, but to participate in a philosophical study required a great deal of reflection and discussion with my supervisors. One of the difficulties with this methodology is to remain ‘phenomenological’ and to try and represent interpretation and meaning from the text. This is challenging as often the words and expressions used by the participants at times were emotional and moving. Their subjective view cannot be isolated always to an accurate interpretation. Sometimes it is impossible to remove some of the emotion,
the use of verbatim interview data demonstrates this well. It was important that my views were not held up as superior and as De Sales Turner (2003) points out ‘it is important to be aware of one’s own bias, so that the text can present itself in all its otherness, thus asserting its own truth against one’s own fore-projections’ (Gadamer 1975). Part of the reflective process for me was also to understand the phenomenological approach or as Munhall (2011) states ‘becoming phenomenological’.

Managing the data also posed difficulties. It was challenging trying to extract key extracts from the interviews to present in the findings when all the interview data appeared to be so relevant and important. I did not want to only represent my own views and had to ensure I constantly kept sight of the aims of the study.

There are other methodological approaches that could have been used for this study; however the rational for phenomenology was clearly outlined in chapter three and was based on the overall aims and philosophical positioning of the researcher.

One of the study’s strengths is that it is the first to explore living with EPS from the “insider’s” perspective. In fact the literature review revealed little research specific to long-term patients on PD. The fact that EPS is such a specialist area of clinical practice lends itself to an increased potential of penetration into the relevant clinical fields. The knowledge gained can therefore form the basis for further research. The participants were also unique in having lived with a long-term condition such as CKD and had managed self-care dialysis treatment for a number of years. This also adds to the growing library on adjustment and self-management in long term conditions. The experience of managing the transition from PD to HD is also an important part of the experience. This adds strength, as the findings can be transferred to individuals living with other long-term conditions and the processes they engage in to cope with the stress of acute setbacks and changes in treatment. This is particularly relevant to CKD, where the technology and the control individuals have is dependent on the dialysis and the relationships they develop with healthcare staff. Transferability of the study findings is an important factor and one that is often used as a measure of its quality (Koch 1996).
6.8.1 Summary and Conclusions

The discussion has focused on the major findings of the study and has clearly demonstrated how the aims and objectives of the study were achieved. To summarise the key points are:

- The early symptoms of EPS were not recognised by patients and HCPs as significant, indicating a gap in knowledge, expertise and communication about EPS.
- Improving and imparting knowledge to patients, families and HCPs to enhance knowledge and expertise is essential for future management of EPS.
- Information needs have been highlighted regarding the risks associated with length of time on PD, and how, when and where the risk of EPS should be discussed.
- Preparation and transition to HD is also an area requiring further input in terms of preparation.
- Study data highlight the major impact that EPS surgery, bodily changes, pain (and inadequacies in its management) and stoma formation had, both physically and psychologically on patients and families.
- Supportive care needs that addresses psychological, social and practical issues may be improved through written information, support groups, spiritual care and financial support.

6.9 Implications for Practice

This section presents a summary of the implications for practice outlined in the discussion.

1. There needs to be an improvement in the provision of information on EPS to patients, families and HCP’s. Information and methods of communication will need to be examined in line with current available written material and other
sources of information provision. In particular, attention should be given to current available prognostic information that utilizes patient input in the process of patient focused information. Specific recommendations are:

- To examine written information to be given at the study site where surgery is offered at the time of diagnosis of EPS. It is recommended that participant volunteers are used to develop the information to outline expectations of surgery and longer term impact. Current information given by surgeons and the coordinators should be examined to ensure consistency.

- To construct a patient information leaflet specifically for those on long-term PD, containing details of when to expect a transfer to HD and the reasons for this, and discussing the risk of EPS. Also included would be a profile of the early signs and symptoms of EPS to encourage patients to seek advice as soon as these symptoms become apparent.

- To examine other information support structures, including the internet and local and national patient groups, to improve awareness of EPS.

- To consider a peer support network for patients diagnosed with EPS. Two participants in this study have offered their support in developing a network as they believe it may be helpful to discuss EPS with another patient who has experienced it.

- To discuss with colleagues the types of risk information that are given to patients at the pre dialysis stage of CKD, to generate ways of incorporating the integrated care concept, care planning and the risks of EPS.

- To consider the educational needs of HD nurses and clinicians in relation to EPS. Publication and presentation of the study findings will go some way to raising awareness within the renal community. I have been invited to speak at a National Conference and provide a summary for potential publication.
within a dialysis journal. It is recommended that current education and training programmes include EPS as a subject (e.g. renal courses for registered nurses and registrar training programmes) should be examined to determine if they included EPS as a subject.

2 To create a profile of the early symptoms of EPS reported by patients. This could be an integrated nutritional assessment of all patients transferring to HD, and should become part of routine clinical practice. Gastrointestinal symptoms would be recorded by renal dieticians. The profile would be fed into the multidisciplinary team, and it could initially form a small research project to assess its effectiveness in detecting the early signs of EPS (see research recommendations below).

3 To examine ways of trying to promote home HD among those that transfer to HD from PD. This would enable patients to continue to self-manage and regain a degree of autonomy. This is already happening in practice within the unit where the study was undertaken; however there are many units who are still limited in the provision of HHHD. Providing patients’ information through local Kidney networks utilising NICE guidelines (2011) and DH (2004) recommendations on the provision of choice and home based therapies, can empower them to seek change. Contacting Kidney Patients Associations and the National Kidney Federation is recommended to consider how this information is shared may need to be considered.

How improvements in practice will be achieved needs to be considered from a local and national perspective. The introduction of the role of the EPS co-coordinator in both specialist centres will be pivotal in enabling some of these recommendations to be discussed and implemented. My role and involvement with teams responsible for the care of patients at risk of EPS and within the centre where EPS surgery is offered will also provide a platform to take forward the key points.
6.10 Research Recommendations

Based on the study’s findings, the following are suggested as potential future topics for research:

- Assessment of gastrointestinal symptoms and nutritional issues in all patients on PD for longer than four years, even after transfer to HD. To assess then the feasibility of a tool or checklist that would indicate early symptoms of EPS.

- Exploration of patient outcomes questionnaires, including quality of life, symptom burden and depression, from the time of diagnosis to the two-year follow-up point.

- Collection of prospective data on the outcome of surgical interventions by the two centres.

- Evaluation of the impact of a ‘competitive risk tool’ on clinicians understanding of the risks of EPS relative to other risks associated with CKD and their associated clinical decision-making. Such a tool will need to be patient focused and include the patient perspective.

- Exploration of the perceived impact of EPS from the perspective of families and carers.

- Exploration of HCP’s views to identify the impact/influence of current EPS guidelines and views of PD management in long-term patients.

6.11 Concluding Remarks

This study has provided valuable insights into how patients live with EPS and experience its management. In terms of originality, there have been no previous studies that examine living with EPS from the patient’s perspective. The present study has yielded some findings that can be directly transferred to clinical practice. Challenging as the issues raised by participants may be, they are nonetheless important, so that future care and management of patients can be improved.
It is with great sadness that it has to be recorded that three of the participants have died since participating in this study, which serves to emphasise the seriousness of EPS – and the fragility of life with CKD.
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*Body and Society, 2*, 23-47.


Appendix 1

Included Studies for Literature Review
<table>
<thead>
<tr>
<th>Author + Date</th>
<th>Aims</th>
<th>Methodology</th>
<th>Participants</th>
<th>Analysis</th>
<th>Results</th>
<th>Quality</th>
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<tbody>
<tr>
<td>Kutner 1987 (USA)</td>
<td>No aims written</td>
<td>Qualitative interviews and observations</td>
<td>ERSD all RRT's N=150</td>
<td>Socio-cultural analysis</td>
<td>Key concepts:&lt;br&gt;- Initial shock&lt;br&gt;- Managing uncertainty&lt;br&gt;- Existing social worlds&lt;br&gt;- Dialysis as work&lt;br&gt;- Sickness/wellness ambiguity&lt;br&gt;- Disability</td>
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<td></td>
<td>Qualitative psychosocial measure</td>
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<td>Gerhardt 1990 (UK)</td>
<td>How patient careers in ESRD can be identified on a long-term basis</td>
<td>Qualitative socio-cultural (biographical) consecutive interviews over 12 years</td>
<td>HD + Spouses N=68</td>
<td>Illness trajectory/biographical representation</td>
<td>3 main careers&lt;br&gt;- Family rehabilitation&lt;br&gt;- Treatment representation&lt;br&gt;- Marriage</td>
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<tr>
<th><strong>Rittman et al 1993 (USA)</strong></th>
<th>To discover and describe shared meanings embedded in the experience of living with CRF</th>
<th>Phenomenological hermeneutic Interviews</th>
<th>HD N= 6</th>
<th>Thematic analysis</th>
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<td>Taking on new understanding of being</td>
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<td>Dwelling in dialysis</td>
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<td><strong>Gregory 1998 (Canada)</strong></td>
<td>To explore patients experiences with + perceptions of ESRD + HD treatment</td>
<td>Grounded Theory interviews</td>
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<td>Meanings of illness/treatment</td>
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<td><strong>Lingqvist et al 2000 (Sweden)</strong></td>
<td>To explore the perceived consequences of illness +treatment</td>
<td>Exploratory descriptive interviews</td>
<td>HD N=30</td>
<td>Thematic/content analysis</td>
<td>Overall theme wishes for independence and normality 4 main categories</td>
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<td>Wish to manage one’s own life</td>
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<td>To describe patient experiences of suffering from ESRD</td>
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<td>Deprivation of one’s normal life Concerns</td>
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<td>Caress et al 2001 (UK)</td>
<td>To explore subjective meaning of illness in CRF</td>
<td>Quantitative survey questionnaire using Lipowski scale and 5 minute interview</td>
<td>Pre dialysis N=155 HD N=103 Transplant N=147</td>
<td>Descriptive statistics</td>
<td>8 part questionnaire ‘challenge’ highest % (62.5)chosen in all groups</td>
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<td>Keeping &amp; English 2001 (Canada)</td>
<td>Not clearly stated other than focus on patients learning as experienced by PD</td>
<td>Qualitative theory-learning</td>
<td>PD N=8</td>
<td>Themes on incidental learning</td>
<td>3 main themes Principle informal learning themes:- Understanding medical language/Trusting own experience/living on boarder life + death Barriers to learning:- Diminished sense of personhood/literacy level Theory of informal and incidental learning</td>
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<tr>
<td>Curtin et al 2002 (USA)</td>
<td>To explore factors that are relevant to</td>
<td>Exploratory descriptive interviews</td>
<td>Long term survivors HD/PD/Transplant</td>
<td>Saturation/ content analysis</td>
<td>Transformation-active self management Adaptation to changed</td>
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<td>Study</td>
<td>Population</td>
<td>Method/Design</td>
<td>Sample</td>
<td>Themes</td>
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<td>King et al 2002 (UK)</td>
<td>ERSF patients ability to not only survive but enjoy good QOL</td>
<td>To explore the experiences of individuals with renal diabetic disease with focus on good adaptation</td>
<td>N=18</td>
<td>circumstances-uncertainty/life constraints/dialysis itself/setbacks</td>
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<td>Walton, J 2002 (USA)</td>
<td>What does spirituality mean to HD patients and how does</td>
<td>Grounded theory interview</td>
<td>HD N=11</td>
<td>2 level integrated themes</td>
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<td>4 first level</td>
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<td>Immediate reactions or diagnosis</td>
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<td></td>
<td>Explanations of renal disease</td>
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<td></td>
<td>Living with renal disease</td>
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<td>Hopes/fears/expectations</td>
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<td>Integrated themes stoicism and uncertainty</td>
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<td>Constant comparative-development of core categories</td>
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<td>Central category –Finding a balance</td>
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<td>Phases-Facing mortality</td>
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<td>Reframing</td>
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<td>Methodology</td>
<td>Sample Size</td>
<td>Findings</td>
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<td>Faber 2003 (Canada)</td>
<td>To understand the life experiences of people living with kidney failure</td>
<td>Grounded theory social cultural interviews/observation/recorded diaries</td>
<td>HHD N=3 HD N=1</td>
<td>Thematic with reflexivity described</td>
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<td>Central theme of ‘work’</td>
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<td>3 sub areas</td>
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<td>Work in the biomedical community</td>
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<td>Work outside the hospital/dialysis setting</td>
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<td>Work entailed in living with consequences of CKD</td>
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<td>Polashek 2003 (New)</td>
<td>Unclear</td>
<td>Qualitative interviews/critical standpoint interviews</td>
<td>HD N=6</td>
<td>Themes/concerns relating to discourse analysis</td>
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<td>Suffering continued symptoms</td>
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<td>Aims were weak</td>
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<td>Methodology</td>
<td>Participants</td>
<td>Data Analysis</td>
<td>Themes and sub-themes</td>
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</table>
| Martin-McDonald (Australia) | To explore contextually dialysis dependent experiences and their Meanings | Qualitative narrative interviews | PD=5 HD=5 | Thematic analysis and continuum themes | Five main themes  
Freedom-Restrictions  
Being normal-being visible  
Control-Acquiescence  
Hope-Despair  
Support-Abandon |
<p>| Curtin et al (2004)     | To identify domains + Exploratory descriptive study interviews | PD &gt; 4 years N=18 | Thematic coding | 3 main themes and subthemes |</p>
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<tr>
<th>(USA)</th>
<th>dimensions of self management experienced by PD patients</th>
<th>Self management</th>
<th>Hagren et al 2005 (Sweden)</th>
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<td>How patients on MHD experience life situation</td>
<td>Autonomy/ control Normality in everyday life</td>
<td>Exploratory interviews HD N=41 Content analysis</td>
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<td>To explore the perceptions of patients with diabetes experiencing kidney failure</td>
<td>Ravenscroft 2005 (USA)</td>
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<td>Not finding space for living</td>
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<td>Feelings evoked in the care situation</td>
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<td>Attempting to manage restricted life</td>
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<td>2 dominant themes with 5 subthemes</td>
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<td>Global experience:- diagnosis, illness intrusion, interactions with HCP’s</td>
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<td>Adjusting to kidney failure:-</td>
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<td>Author(s)</td>
<td>Design</td>
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<td>Data Source</td>
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<tr>
<td>Dekkers et al 2005</td>
<td>3 Lengthy questions but focus on the moral dimension of experiences of patients with ESRF</td>
<td>Interpretive Phenomenology using Aristotelian virtue ethics Semi structured interview</td>
<td>HD + PD N=7</td>
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<td>Giles 2005 (Canada)</td>
<td>Investigate, explore + describe the embodied life-world experience of people who live with a HHD machine</td>
<td>Descriptive phenomenology interviews</td>
<td>HHD N=4</td>
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<td>Velez &amp; Ramasco 2006</td>
<td>To identify patients own beliefs about HD</td>
<td>Exploratory interviews + observation</td>
<td>HD N=15</td>
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</table>

Poor congruity in research methods and
<table>
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<tr>
<th>(Spain)</th>
<th>symptoms causes of illness, expectations, perceived consequences and their ability to control treatment</th>
<th></th>
<th>HD a source of imagery + metaphors</th>
<th>Consequences of living with ESRD + coping strategies</th>
<th>interpretations</th>
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<tbody>
<tr>
<td>Polash 2007</td>
<td>(New Zealand) To describe characteristic attitudes towards their treatment regime among a group living on home dialysis</td>
<td>Qualitative interviews</td>
<td>HHD N=15 PD N=5</td>
<td>Interpretive</td>
<td>3 main categories with sub themes</td>
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<td>Learning their need for treatment</td>
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<td>Modifying therapy to maintain lifestyle</td>
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<td>Motivation from their individual lifestyle</td>
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<td></td>
<td>Lack on congruity of conclusions with findings</td>
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<tr>
<td>Kaba et al 2007</td>
<td>(Greece) To explore impact of culture on experience of</td>
<td>Grounded Theory Interviews</td>
<td>HD N=23</td>
<td>Inductive-Theory development into categories</td>
<td>Theory development of culture &amp; health</td>
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<td></td>
<td></td>
<td>Five categories</td>
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<td>Study</td>
<td>Methodology</td>
<td>Sample Characteristics</td>
<td>Main Findings</td>
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<tr>
<td>Molzhan et al. 2008 (USA)</td>
<td>Secondary analysis of written narratives</td>
<td>All RRT’s</td>
<td>Problems related to symptoms, Limitations to life, Uncertainty, Dependence, Changes in Personality</td>
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<td>Tanyi &amp; Werner 2008 (USA)</td>
<td>Descriptive phenomenology interviews</td>
<td>HD N=16</td>
<td>Acceptance, Fortification</td>
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<tr>
<td>Study</td>
<td>Methodology</td>
<td>Design</td>
<td>Sampling</td>
<td>Data Analysis</td>
<td>Themes</td>
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<tr>
<td><strong>Tong et al 2009 (Australia)</strong></td>
<td>Focus groups</td>
<td>9 Groups CKD stages 1-5 + transplant + HD +PD</td>
<td>Deductive and inductive process to develop themes</td>
<td>5 main themes</td>
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<tr>
<td></td>
<td>To describe the range and depth of experiences, perspectives, meaning, impact on lifestyle and relationships across CKD stages 1-5</td>
<td></td>
<td></td>
<td>Personal meaning of CKD</td>
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<td>Managing and monitoring health</td>
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<td>Lifestyle consequences</td>
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<td>Family Impact</td>
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<td>Informal support structures</td>
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<td></td>
<td>Comparison made across CKD groups</td>
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<td><strong>Moran et al 2009 (Ireland)</strong></td>
<td>Qualitative interviews using hermeneutical phenomenology</td>
<td>HD=16</td>
<td>Thematic analysis</td>
<td>Themes from two publications related to waiting for transplant and waiting for HD</td>
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<tr>
<td></td>
<td>To explore patient experiences of HD</td>
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</table>
Appendix 2

Critical Appraisal Checklist for Literature Review

Yes/no or unclear are answers to the following questions

1. There is congruity between the stated philosophical perspective and the research methodology
2. There is congruity between the research methodology and the research question or objectives
3. There is congruity between the research methodology and the methods used to collect data
4. There is congruity between the research methodology and the representation and analysis of data
5. There is congruity between the research methodology and the interpretation of results
6. There is a statement locating the researcher culturally and theoretically
7. The influence of the researcher on the research, and vice-versa, is addressed
8. Participants, and their voices, are adequately represented
9. The research is ethical according to current criteria or, for recent studies, there is evidence of ethical approval by an appropriate body
10. Conclusions drawn in the research report do appear to flow from the analysis, or interpretation, of the data

(Briggs 2008)
PARTICIPANT CONSENT FORM FOR RESEARCH STUDY

STUDY TITLE: An Exploratory Study of Patients’ Experience of Encapsulating Peritoneal Sclerosis (EPS)

1. I confirm that I have and understood the information for the above study (version 2 Sept 2009). I have had the opportunity to consider the information ask questions, and have had these answered satisfactorily.

2. I understand that my participation is voluntary and I am free to withdraw at any time, without my medical care or legal rights being affected.

3. I understand that relevant sections of my medical notes and information collected during the study maybe looked at by the supervisors of this study from the University of Manchester, from regulatory authorities and the NHS trust. I give permission for these individuals to access this information.

4. I agree to my kidney doctor and GP being informed of me taking part.

5. I agree to take part in the study.

_____________________________  ____________  _________________________
Name of patient                  Date                  Signature

_____________________________  ____________  _________________________
Name of person taking consent    Date                  Signature

When completed 1. For patient 2. For research file 3. Original for medical notes
Appendix 4

Letter to GP

Dear Dr

I am writing to inform you that your patient.......................................................has agreed to take part in a study. The study title and patient information sheet are enclosed.

I currently work as an Advanced Nurse Practitioner at Manchester Royal Infirmary and the study is part of a PhD qualification. Full ethical approval has been obtained from Central Manchester Research Ethics Committee.

The interviews will take place either in the patients’ home or at their own hospital.

I have also included my email address if that is a more convenient way of communicating.

Thank you

Letter to Consultant

Dear Dr

I am writing to inform you that your patient.......................................................has agreed to take part in a study. The study title and patient information sheet are enclosed.

I currently work as an Advanced Nurse Practitioner at Manchester Royal Infirmary and the study is part of a PhD qualification. Full ethical approval has been obtained from Central Manchester Research Ethics Committee.

The interviews will take place either in the patients’ home or at their own hospital. I will therefore need your permission to access them at the hospital if that is their preferred place. If you have any objections please contact me by letter or telephone otherwise I will telephone when I am ready to organise it. A contact for a nurse would be helpful as I can discuss with them directly the logistics of me entering your unit or if there are any specifics regarding the patient you feel would be compromised by the interview process.

I have also included my email address if that is a more convenient way of communicating.

Thank you
Appendix 5

PARTICIPANT INFORMATION SHEET

Title of Study

An Exploratory Study of Patients’ Experiences of Encapsulating Peritoneal Sclerosis (EPS)

I would like to invite you to take part in a research study. Before you decide I would like you to understand why the research is being done and what it would involve to you. I will go through the information sheet with you and answer any questions you have. I would suggest this should take about 20 minutes. Talk to others about the study if you wish. The aim of this sheet is that part 1 will tell you about the study and what will happen if you take part, and part 2 will give more detailed information about the conduct of the study. Please ask if anything is not clear.

PART 1

What is the purpose of the study?

This research is being conducted as part of a PhD qualification from the university of Manchester. The purpose of this study is to explore the experiences of patients who have been diagnosed with encapsulating peritoneal sclerosis (EPS). As research this is called qualitative and is aimed at interviewing patients to obtain detailed perspectives on their experience. This sort of research is useful to help the people who care for you to understand your views and feelings about the illness.

Why have I been invited?

You have been invited as a patient who has been treated for EPS and your name was obtained from your doctor.

Do I have to take part?

Taking part in the study is entirely voluntary, it’s up to you if want to join. I will describe the study and go through this information sheet. If you agree to take part, I will ask you to sign a consent form. You are free to withdraw at any time, without giving reason. This would not affect the standard of your care.

What will happen to me if I take part?

If you take part I will conduct an interview by prior arrangement with you at a convenient time. I will probably contact you by telephone to arrange this. This can be in your home or at your local hospital wherever you prefer. The interview will be as
long as you feel comfortable but I anticipate 1 hour in length. The interview will be very informal and should be directed by yourself, as I would like you to talk freely about your experience. I anticipate that we will meet on one more occasion for a second interview.

The research will be over a one year period which is why I would like to perhaps meet and interview you on two different occasions.

I would plan to record the interview on recording equipment. This is because it's more accurate as it is very difficult to write during our interview, it can also be distracting, as I would like us to have a conversation rather than formal question and answers. The tape will be kept very confidential and no one other than me will know the identity of the participants. At any point during the interview you can stop or rewind the tape.

If you would like a copy of the transcript to check the details this will also be possible. I may contact you once the results have been put together to see what you think of my interpretation of our interview.

I may also ask you to keep a written diary over the course of your recovery, again this will be up to you and you do not have to if you feel unable.

What are the possible disadvantages and risks of taking part?

There should be no risks to taking part in this study as it involves just a discussion. If at any stage during the interview you feel distressed or do not want to continue we will stop. If at any stage you wish to discuss specifics of your treatment I may not be able to help but will certainly contact appropriate personnel if necessary.

I will have contact numbers of counselling or psychological support services should this be required. I do not anticipate this but want you to know that it is there if necessary.

What are the possible benefits of taking part?

None but you may feel you have contributed improvements in care in the future. It is hoped that the results will help health care professionals to give care that meets the needs of patients.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in part 2.

Will my taking part in the study be kept confidential?

Yes. I will follow ethical and legal practice guidelines and all information about you will be handled in confidence. The details are included in Part 2.
This completes Part 1. If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making your decision.

PART 2

What will happen if I don’t want to carry on with the study?

You can withdraw at any time if we have already done an interview I will still use the transcriptions but there will be no identity with the data. You can still keep in contact and if you wish to rejoin the study this will be fine.

What if there is a problem?

If you have any concerns you can contact the researcher whose number will be at the bottom of the sheet, or you can contact the supervisors of the project, contacts also at the bottom of the sheet. Any questions or queries will be dealt with. If you wish to take to make a formal complaint about the study you can contact a University Research Practice and Governance Co-ordinator on 0161 275 7583 or 0161 275 8093 or by email to research-governance@manchester.ac.uk.

Will my taking part in the study be kept confidential?

All information from the interviews and diaries will be kept confidential. Firstly your name will not appear on any of the interview transcripts. The transcripts will then be stored in a database or computer that is password protected so only the researcher can access it. The typist responsible for the transcriptions will not know your name and will also follow ethical and legal practice for dealing with this information. The data will be kept for up to 10 years and will then be destroyed. The reason to keep the data for so long will be because the study and completion will not be until 2011 and further access to the data maybe required during this time frame. Personal information and consent forms will be kept in a locked cabinet and will only be accessed by the researcher, supervisors and auditors of the project.

Involvement of GP of your Kidney Doctor

Your kidney doctor will be informed by letter of your involvement. Your GP will be notified with your permission.

What will happen to the results of the research study?

You may be contacted when all the interviews are complete and analysis is finished. This will be an opportunity for you see if they represent your experiences. If you would like a copy of the summary of the findings this can be arranged and sent to you.

The results of the study will be used in a thesis for a PhD qualification. They may also be used in published article relating directly to the study. There will be no way of
identifying participants but quotes from interviews will be used within the written thesis and publication.

**Who has reviewed the study?**

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Central Manchester Research Ethics Committee.
## Appendix Six

### Original Meaningful statements and Development of Themes

<table>
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<tr>
<th>THEMES</th>
<th>SUBCATEGORIES</th>
<th>HEADINGS FROM MEANINGFUL STATEMENTS</th>
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<tr>
<td><strong>Making sense of it all</strong></td>
<td>Abandonment</td>
<td>Not being heard</td>
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<td>Feeling alone</td>
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<td>Ignored by HCP’s</td>
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<td>Suffering</td>
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<td><strong>Uncertainty</strong></td>
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<td>Looking for answers</td>
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<td></td>
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<td>Uncertain future</td>
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<td><strong>Self Interpretation</strong></td>
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<td>Using own expertise</td>
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<td></td>
<td></td>
<td>Making sense of symptoms</td>
</tr>
<tr>
<td><strong>Meaningful Event Diagnosis</strong></td>
<td>Relief and shock</td>
<td>Being listened to</td>
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| Realisation of illness meaning | Hope  
|                              | Chance to survive  
| Realisation of illness meaning | Desperate times  
|                              | Facing the battle  
|                              | How ill I have become  
| Hero worship | Faith and trust in surgeons  
|              | Treated as an individual  
| Fear | Of dying  
|     | Of future  
|     | Of Stoma  
| **Surviving EPS** | Endurance  
|                          | The surgery and effects  
|                          | Time has no meaning  
|                          | Complications  
<p>|                          | Pain |</p>
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<td>For something to be done</td>
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<td>Feeling Lucky</td>
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<td>Recovery</td>
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<td>Being close to death</td>
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<tr>
<td>Every day a bonus</td>
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<td>Seeing others die</td>
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<td>A new body</td>
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| Family: ‘Not getting through without them’ | Support | Being there  
|                                          |          | Emotions  
|                                          |          | Impact on them  
|                                          |          | Practical support ‘lack of’  
| Protecting them | Keeping it from them  
|                  | Preparing for death  
| Guilt            | What they have been through  
|                  | Witnessing the illness  
|                  | Relying on them  
| Role changes     | Affect on role in family  
|                  | Readjusting  
| Care and dignity | Involvement in care  
|                  | Providing dignity  

Appendix seven

Schema of Themes Using Time Continuum

Chronic illness-Self management-Normality

Pre diagnosis/ Meaningful event Diagnosis Surgery New life meanings

Trying to make sense

Abandonment Relief Endurance New body
Self interpretation Faith in surgeon Desperation Adaptation-still striving
Suffering Facing death Bodily changes No one understands
Uncertainty Realisation of illness meaning Lucky to survive Relationships
Disappointment in HCP’S Acceptance-no choice Enormity Still looking for answers
Not being heard Acceptance-no choice Time has no meaning Loss of PD-freedom

Loss of Control and independence Family impact/support Survivorship-self determination Information needs