Experiences of biographical disruption at critical moments in the lives of young adults with childhood renal failure.

A comparative study of adults aged 16-30 with prepubertal and postpubertal onset ERF.

A thesis submitted for the degree of PhD to the University of Surrey by Helen Lewis
January 2012

This thesis is dedicated to our daughter Caroline Lewis

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Abstract

Chronic illness experience in emerging adulthood is a relatively neglected field in medical sociology and youth transition. This study uses survey data from young adult patients (N=296, aged 16-30 years) on renal replacement therapies (dialysis and transplantation) and interview data from patients, first diagnosed aged 0-19 years (N=40) and their parents (N=20), to explore living with renal failure in young adulthood. Renal failure (ERF) is relatively invisible in society and thus little known and understood. It is rare in children and normally invisible, making disclosure of illness status particularly difficult in young adulthood. The young adults in the study were living with a discreditable condition whose embodiment was highly salient, at a time in their lives when it was arguably more important than at any other, that they appeared healthy and normal.

Grounded theory informed qualitative data gathering and data analysis, and built on concepts derived from the data and relevant literature. Quantitative survey data were used to contextualise the qualitative data, and demonstrate that the study participants were reasonably representative of all young people of the same age with the same condition.

It is already recognised that the age at which someone becomes chronically ill influences their experience of their illness. For the first time, this study shows that the social lives of young adults diagnosed before puberty were experienced differently from those diagnosed after puberty, and differently again from those diagnosed in mature adulthood. The findings show that those who were ill very early in the life course tended to achieve markers of adulthood later than those who were ill after puberty. However, it was socioeconomic and family resources that influenced the trajectory and adult destinations of emerging adults with chronic illness as much as ill health itself; unless the latter made participation in adult social life completely unattainable, temporarily or permanently.
Acknowledgments

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My husband, for his endless patience and support, IT advice and expertise, and proof reading at various stages.

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The staff and patients in the renal units at all the participating hospitals.

The interviewees who provided such rich accounts of their experiences of living with ERF, but found themselves revisiting some difficult and painful periods of their lives.

The parents of the interviewees who contributed to this study, many of whom equally found themselves revisiting some difficult and painful periods, often without having spoken about them before outside the family.
Author's personal statement

This thesis and the work to which it refers are the results of my own efforts. Any ideas, data, images or text resulting from the work of others (whether published or unpublished) are fully identified as such within the work and attributed to their originator in the text, bibliography or in footnotes. This thesis has not been submitted in whole or in part for any other academic degree or professional qualification. I agree that the University has the right to submit my work to the plagiarism detection service TurnitinUK for originality checks. Whether or not drafts have been so-assessed, the University reserves the right to require an electronic version of the final document (as submitted) for assessment as above.
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1 All patients on RRT on hospital databases with date of birth on or between 1.1.76 and 31.12.90.

2 COREC no longer exists, and arrangements for ethical approval are now administered by the National Patients’ Safety Agency.

3 Wherever ‘age 2006’ is used, this is ‘age on 31.12.06’

4 All respondents who were under 23 years, and all those 23 or over with unstable modality (N=150, 51% 296) were excluded from the subset.

5 Stable health means having had no change in RRT modality for 2 years

6 Some interviewees without a definitive diagnosis were born with scarred dysfunctional kidneys. ‘Congenital’ in the table means ‘present at birth’, and genetic means an inherited syndrome.

7 T cells are blood lymphocytes. There are two kinds of T cells: helper T cells and killer T cells. Helper T cells stimulate the B cells to make antibodies, and help killer cells develop. Killer T cells kill the body’s own cells that have been invaded by the viruses or bacteria.

8 The terms ‘prepubertal’ and ‘early onset’ are used almost interchangeably in the 4 analysis chapters, as are ‘postpubertal’ and ‘late onset’, unless either prepubertal (under 11 years) or post pubertal (over 15 years) are clearly preferred.

9 Fourteen of the eighteen interviewees with RRT under 12 were less than 168 cm tall, compared with 6/16 RRT aged 12 or older (not all provided height data).

10 Only Hanna and Gus had never had a transplant.

11 Hanna’s disease was inherited, and her father had a functioning renal transplant

12 Edward not working because was highly immunosuppressed. He was being worked up for an incompatible living donor transplant from his father in the school holidays.

13 Osteoporosis making bones brittle was long-term side effect of RRT

14 Two copies of the faulty gene are needed for it to be expressed in phenotype

15 Only one copy of a faulty gene is needed for it to be expressed in phenotype

16 Usually autosomal dominant

17 Vesicoureteral reflux: urine flows from the bladder back up to the kidney. It causes infections in the urinary tract, which if undetected or frequent, lead to scarring and disease in kidneys
UK and/or European ERF patient survival data for date of birth 1976-1990 incl. were not routinely collected. These are only published data found.

ERF increases with age, so ipso facto there were more older patients in the original sample. Hospital databases varied and most only listed date of birth, gender and modality of RRT, so no refinement of selection criteria was possible.

Personal communication from UK Transplant, 22.12.04

30% survey respondents were registered as having a disability, 22% survey respondents saw themselves as 'having a disability', and 33% survey respondents saw themselves as 'sometimes having a disability' (data not tabled here).

Survey questions 11a, b and c were open text. Responses presented in Table 9, Table 11, and Table 13, were managed using Max QDA and coded by the author.

Number of A-C grade passes at GCSE not available. Interview data revealed that the question, 'What educational level have you reached so far?' was interpreted by some respondents as what they had studied. Applies to all data presented as 'educational level'.

Question added to survey Q9 after pilot stage of survey

Numbers small, percentages not presented

Said they were not well enough to work.

Studied, not passed

Compiled from 2 x 2 contingency tables (not presented) using grouped data from survey questions:

7 a: categories 'very and quite important' combined, and 'not very and not at all important' combined;

7 b: categories 'every day, most days and weekly' combined, and 'rarely and never' combined.

Compiled from 2 x 2 contingency tables using grouped data from survey question 9: categories 'completely and a lot' combined, and 'a little and not at all' combined.

37 interviewees answered this question, data for category 'weekly or more often' only displayed.

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<table>
<thead>
<tr>
<th>Acronym</th>
<th>Extension</th>
</tr>
</thead>
<tbody>
<tr>
<td>APD</td>
<td>Automated peritoneal dialysis</td>
</tr>
<tr>
<td>CF</td>
<td>Cystic fibrosis</td>
</tr>
<tr>
<td>CPD</td>
<td>Continuous/continual peritoneal dialysis</td>
</tr>
<tr>
<td>CKD</td>
<td>Chronic kidney disease, also known as chronic renal failure</td>
</tr>
<tr>
<td>DH</td>
<td>Department of Health</td>
</tr>
<tr>
<td>DMD</td>
<td>Duchenne Muscular Dystrophy</td>
</tr>
<tr>
<td>EMA</td>
<td>Education Maintenance Allowance</td>
</tr>
<tr>
<td>ERF</td>
<td>End stage renal failure, established, enduring renal failure (all used)</td>
</tr>
<tr>
<td>FSGS</td>
<td>Focal Segmental Glomerulosclerosis</td>
</tr>
<tr>
<td>HD</td>
<td>Haemodialysis</td>
</tr>
<tr>
<td>HDU</td>
<td>Haemodialysis Unit</td>
</tr>
<tr>
<td>IH</td>
<td>Intercranial Hypertension</td>
</tr>
<tr>
<td>NHSBT</td>
<td>NHS Blood and Transplant</td>
</tr>
<tr>
<td>NKF</td>
<td>National Kidney Federation</td>
</tr>
<tr>
<td>ONS</td>
<td>Office for National Statistics</td>
</tr>
<tr>
<td>OU</td>
<td>Open University</td>
</tr>
<tr>
<td>PD</td>
<td>Peritoneal dialysis</td>
</tr>
<tr>
<td>PTLD</td>
<td>Post Transplant Lymphoproliferative Disease/Disorders</td>
</tr>
<tr>
<td>QOL</td>
<td>Quality of Life</td>
</tr>
<tr>
<td>R&amp;D</td>
<td>Research and development</td>
</tr>
<tr>
<td>RRT</td>
<td>Renal replacement therapy/ies (ie transplant or dialysis)</td>
</tr>
<tr>
<td>SCD</td>
<td>Sickle cell disease, sickle cell disorder</td>
</tr>
<tr>
<td>Tx</td>
<td>Transplant</td>
</tr>
</tbody>
</table>
1. INTRODUCTION

1.1. UNDERSTANDING RENAL FAILURE

This chapter sets out the rationale for exploring the meaning of living with end stage renal failure (ERF) in emerging adulthood (Arnett, 2000, 2004) for those who were first diagnosed in childhood and adolescence. Scant attention outside medicine has been paid to the social lives of young people with ERF aged 16-30, and there is little professional awareness amongst medical sociologists of the experiences of young adults living with end stage renal disease. The chapter includes sufficient detailed information about the different kinds of renal replacement therapy (RRT), dialysis and transplantation, for the reader to reach a deeper understanding of how treatment technologies used in ERF differ from those used for other chronic diseases beginning in childhood.

Within renal medicine, the psychosocial impact of childhood ERF has been a focus of medical research for several years, particularly in the areas of transfer from paediatric to adult renal services, adherence to RRT regimes, and achievement of measurable markers of adulthood (Bandler, Beehan, Dargie, Dolby, Feehally, Hainsworth et al., 2009; Cameron, 2001; DH, 2006; Marks & Harden, 2008; Rianthavorn, Etteneger, Malekzadeh, Marik, & Struber, 2004; Stam, Hartman, Deurloo, Groothoff, & Grootenhuis, 2006; Watson, Phillips, & Argles, 1996; Watson, 2000a, 2006). The researcher's experience of living with early onset ERF in the family suggests that young people's transition into adulthood is much more problematic than transition from paediatric to adult health services, and possibly more problematic for young renal patients, than for young people with other chronic illnesses or disabilities.

1.1.1. Lay knowledge of ERF

Renal failure in childhood is rare, and almost invisible in society. Its low incidence and resultant low prevalence in children under 18 (Appendix 3, Table 1), mean that many people will live their whole lives without ever knowing, or knowing of, a child or young adult whose life has been affected by ERF. In contrast, diseases such as cystic fibrosis, diabetes, epilepsy, sickle cell diseases (SCD) leukaemias, other cancers, and HIV infection, all appear, for different reasons, to be more socially visible, and are more frequent sociological research subjects (Atkin & Ahmad, 2000; Atkin & Ahmad, 2001; Datta, 2003; Foster, Bryon, & Eiser, 1998; Foster, Eiser, Oades,
Little appears to be known about lay beliefs and knowledge of ERF. Certainly, the portrayal of transplantation in the media as a simple uncomplicated solution to ERF is not borne out by the literature (Crowley-Matoka, 2005; Kierans, 2005). Thus, there is an absence of appreciable lay understanding of the choice, complexity and success of renal replacement therapies, and the social lives of young adult renal patients are spent in social settings where people are generally ignorant of what living with ERF means. Moreover, where renal disease is visible in society, it is seen predominantly as a disease affecting older people, and is not recognised as a disease affecting children and young adults.

Without treatment, ERF is a fatal condition with a very short life expectancy, but, dialysis and transplantation bring their own complex and intrusive disease patterns. Uniquely amongst medical technologies, transplantation of a major organ means accepting a large and ‘foreign’ body into the physical body to replace the functions of a diseased organ. Dialysis means relying on highly sophisticated invasive techniques, involving the insertion into the body of semi-permanent items such as internal catheters, to replace, imperfectly, the function of failed kidneys.

1.1.2. What is kidney failure and how is it treated?

Public understanding of the functions of the kidneys in the body is limited, but essential for reaching a proper understanding of ERF. The body’s two kidneys excrete waste products of metabolism from the body and manage the body’s fluid balance. When kidneys fail, the body is unable to remove toxic wastes, excess water, dissolved salts, and so on, with the result that toxins and fluids accumulate in the blood, people are effectively poisoned, have severe anaemia, high blood pressure, and eventually die. There are many causes of renal failure (genetic, environmental, trauma or injury) or the cause might be unknown. Further information is provided in The National Service Framework for Renal Services (DH, 2004a).

Boys are more likely than girls to develop ERF (3:2, boys: girls) and people of South Asian origin are more likely to develop ERF than the age-equivalent white population (2.3:1, South Asian to white) (DH, 2006 p 9). Up to age 9, about 30 children a year have ERF and are transplanted in the UK, but this number increases around the age of puberty, so that by age 15/16, 80-90 children a year are being transplanted (Appendix 3, Table 1).
Onset of renal failure is often slow (chronic kidney disease, CKD) in both children and adults, but can also be sudden and acute (acute renal failure). In many cases, kidney function deteriorates undetected until ERF is unavoidable. By this time physical symptoms (tiredness, nausea, loss of appetite, high blood pressure and swollen ankles) have made the individual feel very ill, and blood chemistry shows abnormally high levels of urea, creatinine and potassium (creatinine being a key marker).

Four kinds of RRT are in regular use (DH, 2004b), and because they are very different, and because treatment at home is experienced very differently from treatment in hospital, these are explained below.

- **Peritoneal dialysis (PD):** Dialysis fluid is introduced through a catheter into the peritoneal cavity in the patient's abdomen, where it draws waste products and excess water out of the blood using the peritoneal membrane as a filter. The fluid, usually two to two and half litres each time, may be exchanged four or five times per day, as required (usually referred to as CPD, continuous peritoneal dialysis) or a machine may be used to carry out several fluid exchanges.

- **Automated peritoneal dialysis (APD):** Peritoneal dialysis in which a machine is used to carry out multiple fluid exchanges, usually overnight (typically nine hours) and once during the day. It is usually carried out at home. The machine can be transported, with difficulty, in a specially provided very large, heavy and hard, suitcase with wheels.

- **Haemodialysis (HD):** Dialysis in which the patient's blood is circulated through a machine which filters out waste products and excess water. This usually takes around four hours, three times weekly, in a hospital ward or at a specialist satellite unit nearer the patient's home. Increasingly, with new equipment, well established stable patients are being encouraged to haemodialyse at home.

- **Transplantation:** A single donor kidney (living or cadaveric) is inserted into the recipient's lower abdomen, and the blood vessels and ureter are connected to the recipient's blood vessels and bladder. Immunosuppressive medicines are needed for the lifetime of the organ to prevent rejection.

**Dialysis**

Dialysis does not wholly or adequately replace the functions of the body's kidneys, and various dietary changes are needed to correct the blood levels of substances which either accumulate or need replacing. Sodium, potassium and phosphate blood levels need to be carefully monitored and adjusted, and fluid intake severely restricted, often to no more than half a litre of fluid per day. Epoetin (recombinant human erythropoietin) has to be administered up to three times a week to maintain adequate levels of haemoglobin in the blood and prevent severe anaemia. Medicines must also be taken to prevent bone disease and cardiovascular complications. Calorie-rich food supplements might also be needed to address malnutrition. Overall,
the average life expectancy of someone on dialysis (all ages, all risks) is about eight years (UKT oral report 2010). It is difficult to work full time, especially on hospital HD because of the total time taken for travel and dialysis.

Dialysis 'adequacy' tests are used to measure the rate and amount of clearance of key chemicals from the blood. Inadequate dialysis is addressed by spending more time on the haemodialysis machine, or more frequent changes of peritoneal dialysis fluid, larger volumes and/or longer 'dwell' times for those on PD. Both HD and PD need medical and/or surgical intervention at the start to provide permanent access to either the vascular system (HD) or the peritoneal cavity (PD).

Haemodialysis is a sterile procedure. Emergency HD access is usually provided by an intravenous catheter introduced into a deep neck vein or an arterio-venous shunt (bypass), often in the arm. For long-term haemodialysis, these are replaced by a semipermanent arteriovenous fistula under the skin, often the forearm above the elbow, providing large needle access. Careful monitoring is needed to detect blockage or narrowing of the fistula; care is also needed to prevent infection. Prompt action is needed to address any such problems lest dialysis access be lost.

Peritoneal dialysis at home is often the treatment of choice for babies and children, as it offers their families more control over their daily lives. It is more compatible with full-time employment than haemodialysis, but less efficient at removing the toxins. It too is a sterile procedure. For PD access, a minor operation is needed to insert a long catheter through the abdominal skin which tracks along visibly inside the body before entering the peritoneal cavity. The catheter's 'exit site' remains on the surface of the skin and is protected by a sterile dressing. It is a potential source of infection, and bacterial contamination here can quickly lead to potentially fatal inflammation of the peritoneum (peritonitis). Again, prompt action is needed to address any problems either of infection, blockage of the catheter and/or other kinds of 'mechanical' failure.

High levels of knowledge and skill are needed by parents who manage children on HD or PD in their own home, and by all adults who manage either at home. A comparison of the psychosocial burden of haemodialysis with that of peritoneal dialysis for children and their parents (Appendix 3, Table 2) showed that each gave rise to different 'pressures', which varied according to individual circumstances (Reynolds & Postlethwaite, 1996). Lehoux et al (Lehoux, Saint-Arnaud, & Richard, 2004) described the limitations PD imposed on adult working lives, as people were unable to travel for work easily because of the advance planning needed to ensure
supplies of PD fluid and equipment were available, wherever they travelled.

Insurance was also a problem. In addition, PD technology is designed for people with full cognitive and psychological resources and with ‘normal’ physical abilities. Older people, those in poor health, or those with poor access to ‘clean’ environments (at work or home), or incapacities through poor sight, or lack of manual dexterity, find it difficult to operate safely.

**Transplantation**

Kidney transplantation is now accepted as the most clinically safe and cost-effective treatment for most patients with ERF (DH, 2004a). The NHS Blood and Transplant Authority (NHSBT) manages a national transplant database with details of all donors and patients who are waiting for, or who have received a transplant. It provides a 24hr service for matching and allocating donor organs, and makes transport arrangements to get the organs to patients. However, there is a national shortage of kidneys donated for transplantation, and adults spend an average of three years waiting for a transplant. This average waiting time masks an enormous range, from 6 months to more than 15 years for the hardest to match patients. Children up to 18 years have the highest priority overall, and highest priority for the best-matched kidneys. This is in part due to the fact that they are likely to need more than one transplant, and maybe three or even four, in a lifetime.

Patients who are suitable, and who wish to have a transplant, are placed by their physician on the waiting list. There are various criteria for ‘listing’ patients and for allocating kidneys, and not all patients wanting a transplant can be placed on the waiting list. ‘Contraindications’ for transplantation have been agreed across Europe, but are difficult to apply fairly, and it is difficult to demonstrate that they have been fairly applied.

In this country, donor kidneys come, with donor or family permission, from:

- ‘heartbeating’ cadaveric donors, people in intensive care units who are clinically ‘brain dead’;
- ‘non-heartbeating cadaveric donors’, people who have died in hospital, usually in accident and emergency units, in circumstances in which their organs are suitable for donation; and
- ‘living donors’, historically blood relatives, but increasingly blood and tissue-compatible long-term partners, and very recently incompatible family members or altruistic donors.
Kidneys from each of these sources carry different transplantation risks and result in marginally different outcomes. Incompatible living donation involves a very unpleasant 'work up' for the recipient, and remains a 'last resort' at present.

UK data (personal communication from UKTransplant Dec. 2004) suggest that, for first transplants from deceased donors, approximately 90% of kidneys will still be functioning at one year such that dialysis was not necessary. Five-year transplant graft survival rates then were approximately 75%-80%, and 50% of kidneys were functioning after 13 to 15 years. The figures for living donor transplantation were somewhat better, with one-year graft survival rates of 95-98% and 50% of transplants functioning for more than 20 years. These were average data, again masking wide variation.

The transplant operation itself is regarded as risky, though less so than it was twenty years ago, and carries immediate postoperative risks of infection, complications and immediate acute rejection. Post operatively, people must take powerful immunosuppressant medicines to protect the kidney from rejection. Very high levels of these drugs are needed in the first days and weeks post-transplant as the body tries to reject the foreign tissue it has received (acute rejection), making recipients very susceptible to infection. In the longer term, the risk of acute rejection diminishes, and anti-rejection therapy is carefully reduced. However, very few people experience no transplant rejection at all, and chronic rejection affects long-term 'graft survival' for almost all patients.

Long-term transplant maintenance therapy includes permanent immunosuppressant medication, almost always medication to reduce high blood pressure, and medication to maintain normal blood levels of key mineral salts (up to 15 tablets daily). Patients are exhorted to adopt a healthy diet and life style, to stop smoking, reduce alcohol consumption and take plenty of exercise for cardiovascular protection. Adherence to treatment regimes and advice is problematic especially in adolescence and early adult life (Chisholm, Lance, & Mulloy, 2005; Dobbels, Decorte, Roskams, & Damme-Lombaerts, 2009; Feinstein, Keich, Becker-Cohen, Rinat, Schwartz, & Frishberg, 2005; Manificat, Dazord, Cochat, Morin, Plainguet, & Debray, 2003; Nevins, 2002; Qvist, Narhi, Apajasalo, Ronnholm, Jalanko, Almqvist et al., 2004).
1.1.3. Summary of factors affecting adult outcomes for children with organ failure

A recent review by Qvist et al (106 references) (Qvist, Jalanko, & Holmberg, 2003) classified factors affecting, or possibly affecting, psychosocial outcomes and quality of life for children following solid organ transplantation, into pre and post-operative factors (Qvist, Jalanko, & Holmberg, p 1506).

**Preoperative factors (also affect transplant outcomes)**
- Medical disability (disease-specific or secondary to treatment - neurodevelopmental sequelae, growth).
- Presence of psychiatric disorder.
- Chronic severe illness (hospitalisation).
- Age at onset.
- Time factors (transplanted too early or too long a wait).
- Coping strategies in children and their families.

**Additional post-operative factors**
- Graft survival/graft rejection and concomitant feelings of fear, anxiety of death, disease recurrence.
- Medication/treatment side effects (physical effects, such as growth and appearance; secondary organ failure; malignancy).
- Sexual maturation.
- Non-compliance.
- Educational and vocational rehabilitation.
- Financial issues.
- Support from family, social environment, health professionals.
- Attitudes to organ transplantation.

These factors indicate the universality of factors important for this study, especially age at onset, sexual maturation, social rehabilitation and social support.

1.2. NHS RENAL SERVICES

NHS nephrology services are provided via a network of tertiary, secondary and primary health care services across the UK, but renal transplant centres are very limited in number (DH, 2007).

1.2.1. Culture of the adult outpatient clinics
Adult RRT services have been established longer than paediatric services, reflecting the fact the RRT was used in adults before it was considered safe enough for children. Historically, adult services developed at local centres of excellence, thus renal units across the UK vary considerably in size, volume of activity, and characteristics of populations served. Dialysis and transplant adult clinics are often run and staffed separately, and are often large, busy and impersonal places. Until relatively recently there was little acknowledgement of the psychosocial needs of patients, and only limited psychosocial support services are available.

Dialysis clinics (HD and PD) are usually nurse-led with respect to dialysis expertise, and physician-led with respect to overall clinical status and health. If home dialysis is stable, outpatient clinic visits gradually reduce in frequency from monthly to bimonthly or less, unless problems arise. Transplant clinics are physician-led and, post transplant, are attended daily initially. The frequency of appointments is gradually reduced over the first year, to 3-monthly and eventually 6-monthly, if the patient is stable and well. Thus opportunities for professional and peer interaction at transplant clinic decrease as time goes on, and after the first year or so, it becomes unusual for any social interaction with peers to progress beyond polite exchange of pleasantries. Patients attending haemodialysis units have a regular, somewhat inflexible 'shift', usually seeing the same patients there each time. The potential for social interaction between patients on HD is therefore higher, and friendships can be made and 'unmade'. However, the age range of patients on an adult hospital dialysis ward can be from 17-90 years. In contrast, PD at home is potentially socially isolating, with little access to peer support.

1.2.2. Culture of paediatric services
Paediatric renal services are better-resourced than adult services. There is a higher staff to patient ratio, and physicians are trained paediatric nephrologists. Care is holistic and child-centred, and staff have more time for individual children. The extra resources help paediatric units to meet the developmental, educational, and psychosocial needs of children, but more are always needed (British Association for Paediatric Nephrology, 2003).

1.2.3. Transition into adult renal care
In the 1990s, deficiencies were identified in the quality of care provided for paediatric patients with a range of serious diseases moving up into adult wards. Since then, a large volume of medical research has been devoted to how health services might be
improved at this transition (Bandler N, Beehan M, Dargie J, Dolby S, Feehally J, Hainsworth J et al., 2009; Harden & Nadine, 2006; Hartman, DePoy, Francis, & Gilmer, 2000; Jordan & McDonagh, 2006; Kennedy & Sawyer, 2008; McDonagh, 2005; McDonagh & Kelly, 2007; Shaw, Southwood, & McDonagh, 2004a; Watson, Phillips, & Argles, 1996; Watson, 2000a, 2005, 2006). However, concerns from renal paediatricians remain (McDonagh & Kelly, 2007; Watson, 2005, 2006), and a recent initiative is now focusing on service provision for renal patients aged 18-25 years (DH, 2009).

Limitations of medical psychosocial studies of ERF in childhood
Qvist et al (Qvist, Jalanko, & Holmberg, 2003) described limitations to the psychosocial medical studies of solid organ transplantation, and highlighted the lack of consistency and comparability across the various studies, and challenges in identifying variables by which to measure rehabilitation and psychosocial adjustment of children. They observed that much of the existing literature failed to take into account the age of the child, so that all young children and adolescents were included as 'children'. Few studies examined social outcomes, while many more focused on mental health. Moreover, studies largely reflected the philosophy and practice of paediatric nephrology in the single renal centres where they were conducted.

Qvist et al (2003) did not draw attention to the limitations of quantitative research per se, nor to the differences between research which is 'top down' medicine-led and that grounded in the experience of patients. Almost all of the biomedical studies discussed used ‘objective’ health measures, often ‘controlled’ studies, providing renal health professionals with comparisons of their patients' data with those from ‘normal’ children. Most aimed to offer generalisable learning about how patient outcomes might be improved by changing service provision. However, it can be argued that much of this research was concerned with reinforcing the ‘myth’ that renal transplantation brings a return to health and ‘normal’ life, and many studies reported surprisingly high quality of life (QOL) scores on ‘generally accepted’ standardised QOL surveys of transplanted patients.

Joralemon and Fujinaga (1996) challenged renal transplantation research in terms of its methodology, but more importantly its independence, and the financial motives lying behind much of the research, which was often funded by drug companies. They advocated a more financially independent approach, and also one which would pay attention to the meaning of renal disease for individuals. They suggested that anthropological and ethnographic methods would address the deficits in the ‘sterile,
meaningless exercise' (Joralemon & Fujinaga, 1996, p1266) of comparing cases and
generalizing from them out of context.

Today, much renal research remains funded by drug companies, especially those
involved in finding and developing new immunosuppressant agents, and little has
changed with respect to access to research funding. It is difficult to get non-clinically
'derived and located' renal research funded, and there are few, if any, independent
studies of patients with ERF. Slowly, more studies with a qualitative research
'element' are appearing in the literature, but they continue to be led by health
professionals, and few focus on the early years of adult life (emerging adulthood).

1.3. FOCUS OF THIS STUDY

At the outset, the researcher's professional and personal experience included a
general knowledge of the medical literature on transition. Early professional work
related to children with other long-term medical conditions and work with
marginalized and disadvantaged young people meant that this study originated from
her knowledge of professional practice and literature in these fields. She was aware
that children with diseases such as diabetes and juvenile onset arthritis had better-
developed and better-resourced transition services than young renal patients. Her
own 'lived' experience of childhood ERF in the family and knowledge of the literature,
meant she was aware of the kind of challenges that young people growing up with
chronic illness faced in relation to education, employment, forming partnerships and
having a 'normal' family life. Limitations of the renal literature meant that the
experiences of children living with RRT through crucial stages in the early life course
were under-researched.

The sociology of chronic illness, in particular, offers the opportunity to reframe the
kind of research questions posed by health professionals, and ground them in patient
and carer experience. However, there is still a need, if findings are to be considered
valid outside medical sociology, for evidence that any new study is not conducted in
ignorance of prior medical research and knowledge in this field, and that research
subjects are demonstrably representative of the UK population of young adults with
ERF. The researcher knew from experience that she needed to generate sufficient
statistically significant survey data to counter accusations of using 'anecdotal'
evidence, and ensure attention would be paid to the findings by adult renal
physicians. It was also important sociologically for qualitative findings to be presented
in the context of a larger quantitative study of the same population. The researcher’s scientific professional background made her comfortable with both.

This study seeks to address omissions in existing literature by examining the lived experience of ERF early adulthood in the context of the sociological studies of chronic illness and academic studies of youth transition. It aims to contribute towards understanding the meaning of living as a young adult in the UK with an established physically and metaphorically 'invisible' serious chronic condition, using methods derived from several research perspectives.

1.3.1. Aims

To explore the meaning of the chronological age at which serious chronic illness begins for the remaining life course of those affected, including:

- comparing the lived experience of chronic illness in young adults (aged 16-30) who became ill in early childhood, with the experience of those who became ill at or after puberty, using ERF as exemplar;

- examining sociological concepts derived from studies of adults with chronic illness, and exploring how far these explain the lived experience of young adults; and in particular exploring biographical disruption, identity, stigma and presentation of self in invisible and visible chronic disease, and the special role of the physical body in the early life course;

- looking at fragmentation of the life course trajectory, critical moments, and the period of 'normal' adult transition associated with post modernity, conceptualised as 'emerging adulthood';

- examining concepts related to transition for disadvantaged and marginalized youth, and exploring how far these pertain to the lived experience of young adults with chronic illness;

- exploring the role of social structures and social resources in the family in mitigating or exacerbating the lived experiences of chronically ill young adults in childhood and emerging adulthood.

1.3.2. Structure of thesis

In Chapters 2 and 3, sociological, youth and qualitative renal research literature, pertinent to the lived experience of serious chronic illness, is reviewed. Chapter 2 examines biographical disruption and the life course, and Chapter 3, chronic illness, identity and embodiment. Attention is drawn to gaps in the literature and how this study aims to address these gaps.
Chapter 4 describes how the study was approached and conducted. It begins with an overview of relevant methodological literature, and details the way the study was carried out, and data generated analysed, in the context of relevant sociological literature.

The analytical chapters 5-8 deal in turn with:

- the meaning of living with ERF in young adulthood;
- biographical disruption and chronic illness in childhood, adolescence and early adult life;
- emerging adulthood, employment and social identity;
- transition into independence and intimate social relationships.

Chapter 9 discusses the analytical findings in the context of the literature reviewed. Chapter 10 draws conclusions, both in terms of the meaning of living with ERF as a young adult, and in terms of the implications of the findings for emerging young adults with other chronic diseases. It discusses how the findings contribute to existing chronic illness theory, and its wider applications, including implications for health and social care service providers.
2. LITERATURE REVIEW OF BIOGRAPHICAL DISRUPTION AND THE LIFE COURSE

2.1. INTRODUCTION

This chapter discusses the various bodies of literature relevant to the experience of living with chronic illness at various stages in the life course, and focuses on childhood, adolescence, and the early years of adulthood. The main focus is on the youth and sociological literatures pertaining to transition into adulthood and young adulthood. Definitions of social capital used in this and subsequent chapters are appended (Appendix 1).

The powerful role that science and medicine played in the 20th century led to the so-called medicalisation of the normal age-associated processes of human maturation (2005) and the linearity of the trajectory from birth to death. Arber and Ginn (1995 p 5-12) usefully differentiated between chronological age, social age and physiological, or biological age. In particular, they describe social age (related to the psychological concept of age identity), as referring to the social attitudes and behaviours which are seen as age-appropriate at any chronological age, and physiological age, as a medical construct, referring to the physiological and anatomical changes in the human body as people age.

2.2. GROWING UP WITH CHRONIC ILLNESS

2.2.1. Childhood

Childhood is quite rigidly defined in the biological and medical sciences as the period from infancy through adolescence to young adulthood at 16 or 18, and this definition shapes health service provision for children and young people. Thus, chronological age largely determines when adolescents with chronic illness or disabilities move from paediatric to adult health services.

Sociologists prefer to use the more nuanced concept of ‘life course’ to account for changes in the life trajectories in Western society, reflecting their understanding of the how biological and social development are interconnected. However, stereotypical views continue to exist in most societies of what constitutes ‘normal’ behaviour in different parts of the life course. In the west, childhood is socially constructed as a time of dependence when young people develop and anticipate
adult roles and statuses, and adulthood as a time of autonomy, self-determination, choice and independence (Gibson, Zitzelsberger, & McKeever, 2009; Hockey & James, 1993).

A family's sense of what counts as 'normal' for their child has been described as being based 'primarily on their knowledge of other children in their immediate social context, and secondarily on expert definitions …' (Leiter, 2007 p 1638). In contrast, what medical opinion considers normal is based on the 'normal distribution' of an attribute in the population studied, and child health is 'constructed through professionally derived physical, developmental and social criteria' of normality (Leiter, p 1630). Health professionals' ideas about 'normality' accompany every child from birth (Crawford, 1994; Grob, 2008; Petersen, 2006), so that disability and/or ill health are not only biological/physiological manifestations, they are socially created by professionals, who evaluate difference and ascribe labels.

Role of the family

'Normal' socialisation begins when a child is born, and the family, especially the mother, plays a key role in preparing children for a wider world that is itself continuously adapting to social change (Craig & Scambler, 2006). For the families of children who are chronically ill, the whole of family life is interrupted, and it is the family which tries to sustain family life and normal family practices, but agency and social structure 'interact both to constrain and sustain everyday life as normal' (Gregory, 2005 p 389). For children themselves, who are ill from birth or infancy, 'normal' is being ill and coping with the manifestations of illness.

Prout et al (Prout, Hayes, & Gelder, 1999) discussed how parents and children adapted to childhood asthma by constructing a sense of the 'ordinariness' of their daily treatment, as did the families of children with diabetes, enabling the children to be perceived by their families as different but normal; 'normal', in the sense of what they were used to. Research on mothers of children with disability highlights their struggles to maintain the normality of their children's childhood and the 'personhood and value of their children, and to obtain resources within a broader context of body normativeness, exclusion and inequity' (McKeever & Miller, 2004 p 1177).

Chronic illness early in childhood disrupts early socialisation, and key stages of social development may be missed if much of children's early childhood is spent in hospital away from their peer group. When they join their peers at school, identifying with them through social interaction can be difficult. They grow up in the 'clinical gaze',
and constant comparisons medical experts make between them and 'normal' children serve to locate the 'problem' of illness and/or disability within the children themselves (Leiter, 2007). Thus, professional ideas of normality make them feel different from normal, and only gradually, as they get older, do they develop their own, perhaps different, understanding of normality and/or disability, through their own lived experience. In the extreme case of terminal illness, children can still be 'struggling with major issues of identity in the face of a foreclosed future' (Stillion & Papadatou, 2002 p 302).

The impact of RRT on children's families was recognised in the earliest days of treating ERF in children in the US (Hickey, 1972).

'The parents must learn a whole new set of adjustments ... siblings who have had competitive feelings and resentment because of special favors and privileges accorded the ill child may add to the difficult readjustment of parents and patient. At times even the marriage itself must be rebuilt and the entire family recast' (Hickey, 1972 p 395).

Later research shows that in families with disabilities and some chronic illnesses, including ERF, difficulties in family relationships and family breakdown are relatively common (Anthony, Hebert, Todd, Korus, Langlois, Pool et al., 2009; Dobbels, 2007; Shandra, Hogan, & Spearin, 2008). Living donation in solid organ transplantation adds to the distress of families and siblings in childhood (DiMartini, Cruz Jr, Dew, Fitzgerald, Chiappetta, Myaskovsky et al., 2012; Yoshino, Toshono, Kusano, Mizuta, & Kawarasaki, 2007), so that maintaining a 'normal' family environment in ERF is especially challenging.

Ill health of children has been shown to decrease the social capital available to families, not only in education and employment but also in resources such as time available to invest in social networks (Marmot, 2010). In early work, Kazak (Kazak, 1987; Kazak & Nachman, 1991; Kazak & Wilcox, 1984) found that the social networks of families with so-called 'handicapped' children were smaller and more dense than for comparison families, especially for the mothers. Thus affected families were likely to have less support than they would otherwise have had.

More general educational research on 'adversity' has illustrated how adult underachievement in academic learning, social and psychological development is directly related to childhood adversity, and how long it lasts. Where children experience adversity before they are 7, it has a strong negative impact at 26, and
further childhood adversity increases its effect (Schoon, Wiggins, Bynner, Joshi, & Parsons, 2002).

2.2.2. Adolescence

Physiological perspectives
Adolescence has an important physiological context (Krowchuk, 2010). The chronological age at which puberty begins is biologically determined, and has been decreasing in Western society over recent decades. At the same time social maturation, in terms of progress to adult independence, has become increasingly delayed (ONS, 2009). Chronic illness of any kind may delay biological maturation (growth and sexual), as well as social and psychological maturation. In CKD, for example, the onset of puberty is often delayed, and puberty puts extra strain on already damaged kidneys (McDonagh, 2005; Riantavorn, Ettenger, Malekzadeh et al., 2004). Thus a number of children with (un)detected CKD suddenly enter ERF at puberty resulting in an increased incidence of ERF in this age group. Postpubertal sexual and reproductive health are also problematic in ERF (El-Husseini, Hassan, Sobh, & Ghoneim, 2009; LaRosa, Jorge Baluarte, & Meyers, 2011).

Sociological and psychological perspectives
Arnett (2000; 2001; Arnett, 2004) distinguishes between three age-related periods of young adulthood: adolescence (13-19 years), emerging adulthood (20-29 years) and young to midlife adulthood (30-55 years). In all groups, individualistic criteria, such as taking responsibility for their own actions, deciding on their beliefs and values, and becoming financially independent, were most important, and role transitions (e.g. marriage) least important. Adolescents remained largely dependent on their parents, and attached more importance to biological transitions than other groups, perhaps because of their immediacy. Both younger groups were less likely than midlife adults to consider compliance with societal norms important, and were thus more likely to involve themselves in norm-violating behaviours. Interestingly, 19% adolescents, 46% emerging adults and 86% young to mid life adults saw themselves as having reached adulthood (Arnett, 2001).

Psychologically, the development of their own adult identity, separate from their parents, is one of the most important tasks adolescents face. Autonomy is widely acknowledged by social psychologists as essential for human thriving (Galambos, Darrah, & Magill-Evans, 2007; Sheldon, Kasser, Houser-Marko, Jones, & Turban, 2005; Zebrack, Chesler, Penn, Bleyer, & Barr, 2007). Adult identity development involves not only developing greater independence and competence, but also a
number of skills related to cognition, and the ability to take control and responsibility for their own lives (agency), exercising choice and self-determination.

Sociologists see adolescent identities, behaviours and cultures as highly variable and as socially constructed. Identity development, mediated by social interaction, takes place in a structural context which both influences and limits adolescents’ progress: their own social background, their family, peers and their institutional environments (Evans, 2002; Osgood, Ruth, Eccles, Jacobs, & Barber, 2005; Rianthavorn, Ettinger, Malekzadeh et al., 2004). Gender becomes more salient, and adolescence is characterised by heightened social pressure of all kinds, including pressure to conform to gender expectations (Shakib, 2003). In particular, adolescents today are subjected to commercial messages and pressures, especially around sexualisation, body image and gender, which are seen as potentially harmful to their physical and mental health (Buckingham, 2009).

Kirk (2010) described how children and adolescents (8-19 years) using intrusive medical devices had additional identity work to do, as they endeavoured to incorporate their illness, and medical technologies such as CPD, gastronomy, and parenteral nutrition, into their social and personal identities. The children continually worked to normalise their lives, controlling their bodies and information about their condition, in order to manage their identity and peer relationships.

Participation in peer activities is key to peer identification and sharing physical activity is important for many (de la Haye, Robins, Mohr, & Wilson, 2011), as is sharing ‘fast food’, usually high in sodium content. However, while the former can be difficult for those with chronic illness, the latter is incompatible with professional exhortations to eat healthily (Stead, McDermott, MacKintosh, & Adamson, 2011). Moreover, some adolescent masculine practices were more injurious to health, such as drinking alcohol to excess, than feminine practices (Courtenay, 2000).

Some researchers (Johnson, Berg, & Sirotzki, 2006; Laz, 1998; Rozario & Derienzis, 2009) have conceptualised adolescent ‘age identity’ as a performance; performing their ‘age identity’ enabled adolescents to negotiate their own social interactions and gave meaning to others’ performances. Such performances were dependent on the adolescent meeting peer expectations of age-related growth and maturity, both of which might be adversely affected by chronic illness. A study of ‘normal’ American high school children showed no significant relationship between height and measures of friendship with peers, but shorter students were perceived by the younger students
as being younger than their years (Sandberg, Bukowski, Fung, & Noll, 2004). As adolescents with prepubertal ERF are often very small, this suggests that they are likely to be seen as younger than their years.

Some researchers (Arbeau, Galambos, & Jansson, 2007) have distinguished between subjective age (how old one feels) and chronological age, and report that in adolescence, dating, sex and substance use, lead to an older subjective age. However, the same team reported that young adults with motor disabilities, aged 20-30, were no different from 'normal' young adults in their experience of subjective age (Galambos, Darrah, & Magill-Evans, 2007).

Studies in the chronic illness literature and elsewhere have linked teenage rebellion to risk-taking behaviours (Bjork, Knutson, Fong, Caggiano, Bennett, & Hommer, 2004) and non-adherence to medical advice and treatment (Berquist, Berquist, Esquivel, Cox, Wayman, & Litt, 2008; Cochat, De Geest, & Ritz, 2000; McDonagh, Southwood, & Ryder, 2000; Nevins, 2002; Riantavorn, Ettenger, Malekzadeh et al., 2004; Williams, 1999). However, achieving independence from parents and other adults could be seen as incompatible with following strict medical advice without question, and 'risk-taking' behaviours need to be seen in the context of current understandings of 'risk-taking'. Some adolescents do not accept the existence of the risk, and others feel it can be better to be a risk-taker, than a victim of forces beyond their control (Peretti-Watel & Moatti, 2006).

However, in spite of more nuanced academic perspectives, adolescence continues to be stereotyped in the media as a period of gross disruption with breaches of 'acceptable to adults' social behaviour. Whilst it may be seen as normal for adolescents to 'rebel' against authority in order to achieve adult autonomy and independence (Loeber & Hay, 1997; Steinberg, 2000; Wikstrom & Loeber, 2000), rebellion is still seen to offend the orderly construction of the social world, and serious rebellion is problematic.

### 2.3. NORMAL YOUTH TRANSITION

#### 2.3.1. Emerging adulthood

The age at which young people fulfil roles perceived as adult, and identify themselves as being adult, has been rising in the 20th century. Young adults are spending longer in education, more are living independently before having a family, and more are delaying marriage and child bearing (ONS, 2009). Emerging adulthood is
‘characterised by a high degree of demographic diversity’ (Arnett, 2000 p 471), and is distinguished by change, greater independence from parents, and a prolonged period of exploration of adult roles which is relatively independent of the social roles and social expectations of adulthood. However, not all emerging adults are equally able to use these years to explore their future life direction in terms of love, work and world views; some are limited by social and structural factors (Evans, 2002).

**Markers of adulthood**
There is a large body of quantitative youth transition literature which focuses on how far young people have achieved so-called markers of adulthood and the factors that have affected their progress.

The quantifiable markers widely used are:

- full-time employment,
- stable independent accommodation,
- a social support network independent of parents,
- a network of intimates and friends,
- intimate partnership, with or without children,
- a socially determined set of adult skills and abilities,
- a stable adult identity.

Benson & Furstenburg (2003) suggested that while demographic markers of transition were important to young people themselves, especially having a child and moving out of the family home, it was the combination of such markers (getting a job and moving out) that was most important to them. Moreover, if a ‘reversal of position’ meant a return home, then that decreased their subjective feeling of being adult.

There was also a suggestion that working class youth tended to move more quickly through transitions with fewer resources than middle class youth. Salmelo-Aro et al (Salmela-Aro, Aunola, & Nurmi, 2007) described how emerging adults’ goals changed as they got older, and they focused less on developmental goals and friendships, and more on employment, family and health tasks.

However, self-perceived adulthood is not necessarily related to the age of attaining external markers, but related to psychological markers such as a positive adult identity, taking responsibility for themselves, and making independent decisions, as much as to demographic markers (Arnett, 2000, 2001; Fadjukoff, Kokko, & Pulkkinen, 2007; Shanahan, Porfeli, Mortimer, & Erikson, 2005). Moreover, Schwartz et al found that young adults who had ‘stable, coherent and commitment-based identities’ (Schwartz, Cote, & Arnett, 2005 p 224) were well prepared for transition into adulthood, but others might require external support.
Bynner (2005) observed that US transition studies like these (Arnett, 2000, 2004; Benson & Furstenburg, 2003) paid too little attention to European theories of transition in the context of social change, specifically, the importance of social and institutional structural factors, and social inequalities. He called for a greater focus on structural factors and mechanisms of social exclusion. Johnson et al (Johnson, Berg, & Sirotzki, 2007) showed that young people's sense of feeling adult was based on their own socially structured experience, so that what they saw as most important varied with respect to race/ethnicity, socioeconomic status, and age. They argued that both demographic markers and subjective feelings were important, and that both role transitions and personal qualities were associated with age identity.

2.3.2. Trajectories of transition into adulthood

Fragmentation of life course and individualisation

Sociologists in Europe have observed that adult social life is a much less standardised experience than it was in the earlier part of the 20th century, and the life course has become more flexible and fragmented, and less clearly gendered. Individuals today might miss part of the linear life course altogether, or reverse the once-prescribed life course order by returning after a time gap to complete an earlier phase of the life course, such as higher education, they had previously missed. This loss of linearity and resultant fragmentation of routes into adult life has been demonstrated clearly across UK society (Brannen & Nilsen, 2002; Thomson, Bell, Holland, Henderson, McGrellis, & Sharpe, 2002), and, together with the development of a technologically-based society has led to new theories, such as 'structured individualisation' (Beck, 1992; Giddens, 1991; Giddens, 1994).

In 'structured individualisation' theory it was argued (among other things) that social class no longer had the same structuring role in people's lives that it once had, and traditional structural divisions of gender, class, family roles and age were less important in shaping destiny than individual choice. 'Individualisation' was closely linked to new ideas about how individuals construct their identity by self-reflecting, self-monitoring and self-regulation, a process of 'self-reflexivity'. Theoretically, through this, the 'self' can be freed from structural constraints and previous obsolescent rules, norms and traditions, and be defined as a self-reflexive capacity or self awareness (Adkins, 2001; Beck, 1992; Giddens, 1991; Melucci, 1996). Then, 'identity work', consisting of processing and reordering self narratives, can be seen as the key, not only to successful social relationships, but also to an increased ability to exert agency over one's life. Giddens (1991) described times when events come
together to present a 'crossroads' in people’s lives involving a choice of actions, or
when people receive information which totally changes their future lives, as ‘fateful
moments’. He argued that people made their own ‘luck’, through generating new
skills and taking actions to progress their lives (agency), but recognised the important
role played by chance or luck at such moments.

Bounded agency
However, the risks attending ‘fateful moments’ are not uniformly distributed in society,
nor are the skills to use them beneficially (Beck, 1992); some people are much more
at risk of failure than others, often those at social disadvantage. For example, Ford et
al (Ford, Rugg, & Burrows, 2002) reported that the main constraints affecting young
people’s transition into independent housing in England were income, access to
benefits, access to local housing and family support. For many young adults,
especially those who are disadvantaged, agency is limited, and the rhetoric of choice
makes them more unhappy about their perceived lack of it (Brannen & Nilsen, 2005).
Largely invisible social processes, related to gender and social class, can act like an
‘invisible hand of power’ at transition, disproportionately disempowering those whose
lives are more structurally constrained (Brannen & Nilsen, p 424).

Thomson et al (Thomson, Henderson, & Holland, 2003) argued that individualisation
theory did not sufficiently take into account the importance of the duties and
obligations of belonging to a community, and how these act against individualisation,
and the efforts of young people to create their own biographies. Their in-depth study
illustrated how young women saw education as a way out of their socially deprived
backgrounds into a more middle class life, but how structural factors within the
community, mediated by such attitudes as loyalty and not getting ‘above themselves’,
locked them into ‘places, responsibilities and obligations’ that were both gendered
and classed (Thomson, Henderson, & Holland, p 45). These prevented them from
making the most of their educational opportunities.

Evan’s study of young adults aged 18-25 used the concept of constrained or
‘bounded agency’ (Evans, 2002 p 262) to capture the feelings of ‘frustrated agency
and struggle’ that characterised everyday experiences of many disadvantaged youth
in overcoming boundaries with structural foundations in attributes such as gender,
social class, and educational inheritance, and institutional environments. These
prevented them from exercising agency fully.
Critical moments
Thomson et al (Thomson, Bell, Holland et al., 2002) suggested the slightly different concept of ‘critical moments’, as moments with important consequences for young people’s (16-19 years) lives. They discussed how their empirically grounded notion related to, but differed from Giddens’ more theoretically-derived concept of ‘fateful moments’, and argued that, for young people, social structure, as much as individual choice and ability to act to achieve change, played an important role in shaping their lives and their ability to respond to adverse events (Thomson, Bell, Holland et al., 2002, p 338). They divided critical moments for young people into seven groups, related to family, death and illness, education, rites of passage, leisure and consumption, moving house/town/country, and relationships. Amongst these, the diagnosis of chronic illness, for themselves or a family member, had been a critical moment for some.

A diagnosis of long-term serious illness in childhood/young adulthood appears to be a critical moment, ‘fateful’ (Giddens, 1991) in the sense of presenting a ‘crossroads’, but a crossroads where choices and agency are limited by youth and social resources. It is difficult to see chronic illness in young people as empowering, except perhaps in terms of ‘personal growth’, improving access to employment, or as benefiting society by forming a new support group, (Aujoulat, Marcolongo, Bonadiman, & Deccache, 2008; Breckenridge & Vogler, 2001; Locock & Brown, 2010; Moos, 2002).

Transition pathways
The way that young people (18-30) conceptualise and experience time plays a role in their lifecourse thinking at transition (Brannen & Nilsen, 2002). Many young people in training and education are uncertain about their futures, and Brannen and Nilsen introduced the concept of ‘extended present’ (2002 p 517) to describe how, for them, the future was now, so that instead of thinking and planning for the future, they focused on the immediate present and enjoying themselves, experimenting with possibilities. Their analysis of earlier data (Nilsen, 1999), identified three ‘models’ of how young people foresaw their future lives:

- deferment - following the pattern of their parents, one day they would settle down, but now they were young and enjoying themselves;
- adaptable - moving into adulthood one step at a time, trying out jobs, controlling and managing future risk as they went along;
- predictable - already set on clearly charted courses.
Anderson et al (Anderson, Bechhofer, McCrone, Jamieson, Li, & Stewart, 2005) reported that most of the young adults (20-29) in their 1999 study, envisaged the future over quite long periods of time and felt in control of their lives. However, it was only those who were single and/or childless and in work, who were likely to make long-term plans for the future. In contrast, those who lived in insecure circumstances (25% of sample), such as being ‘burdened with children’ or unemployed, were only able to live in the present, or think a few weeks ahead. These methodologically different studies (Brannen & Nilsen, 2007) both drew attention to the challenges of transition facing socially disadvantaged young people.

Ford et al (Ford, Rugg, & Burrows, 2002) identified five typical pathways into adulthood: chaotic, unplanned, constrained, planned (non-student) and student, depending on whether the move was intentional, unexpected or forced, constrained by income or lack of family support. Age, gender and/or ethnic background were associated with particular pathways; men stayed at home longer than women, and were more likely to return home at least once; young adults from ethnic minority groups were also more likely to return home; and black Caribbean people were more likely to be homeless than Indian, Pakistani or Bangladeshi.

Hockey (2009) explored the kind of lives ‘normal’ young mixed gender couples in their 20s anticipated, and observed that their life course trajectories were neither ‘destructured’ nor ‘standardized’, but that they experienced a tension between these different trajectories, and they planned lives together that adhered to competing priorities and values with respect to gendered patterns of work, consumption and fertility.

Persistence of linearity in youth transition
It remains difficult to get away from a dominant trend in social discourse to categorise people by age (group) throughout their life course, not least because age is a readily accessible, universally recognised and convenient survey tool, and often life course perspectives, themselves, refer to age-graded life patterns with both longer term trajectories and shorter periods of transition from one life pattern to another (Leiter & Waugh, 2009). Many young people still follow traditional patterns into adulthood as exemplified by their parents’ lives, and structural constraints of gender and social class remain critical in shaping their future life courses and their approach to the future (Brannen & Nilsen, 2005; Brannen & Nilsen, 2002; Thomson, Henderson, & Holland, 2003).
Temporal roles in society are constructed so that there are ‘normal’ ages at which society expects children to go to school, leave school and move into work, become independent of their parents and set up their own home, and there are legal requirements to fulfil certain age-related roles, such as attending school. Embedded in such ideas are societal norms and understandings of what is the ‘right and proper’ use of time as a good adult citizen. Failure to make ‘proper’, that is age appropriate use of time, at a point in the lifecourse normally associated with employment or education, for example, can have damaging effects on those adults not employed or in training, especially males who cannot work because of ill health (Gibson, Young, Upshur, & McKeever, 2007; Gibson, Zitzelsberger, & McKeever, 2009). By extension, failure to achieve the so-called normal goals of adulthood at an age-appropriate time is likely to be perceived as stigmatising, especially for men; although Fussell and Furstenburg (2005) have argued that differences between the roles of men and women are fewer now than they were in the first half of the 20th century.

Overall, whatever the trajectory of individual lives at transition, conceptualisation of life as linear is widespread, and carries with it the idea of time passing, and the related need for forward progression from school into work and raising a family. Chronological age is particularly important in emerging adulthood when young adults continuously compare themselves with their peer group.

2.4. TRANSITION FOR DISADVANTAGED YOUTH

The quantitative and qualitative studies reviewed in this section situate emerging young adults with chronic illness or disabilities in the larger group of so-called ‘vulnerable’ or disadvantaged youth in Europe and the US, and identify social and structural factors that influence different transitions into adulthood, as appropriate.

2.4.1. Transition into adult health care

Young people ill for the first time at 16 might be admitted to paediatric or adult care; in either case hospital admission is a shock, and neither environment is ideal for young adults (RCPCH, 2003). Adolescents already in paediatric care move into adult care, usually between 16 and 18, but transition to adult services brings an uncomfortable confrontation with the rigidity of the social structures of adult social care and health services (NCCSDO, 2002), an experience of ‘biographical disruption’ which affects only chronically ill children and those with disabilities who survive to young adulthood.
A study of the impact of chronic illness on the life course of young adults (aged 18-30) in the Netherlands (Stam, Hartman, Deurloo et al., 2006), showed that most achieved significantly fewer developmental milestones (autonomy, psychosexual and social development) than their peers, or reached them later. Hartman et al (Hartman, DePoy, Francis et al., 2000) observed that individuals and their families were burdened by 'multiple and uneven responses' (p 55) from educational as well as health care providers, especially where young adults did not match age-related developmental norms at transition into adult services.

Key concerns for adolescents in primary care and hospital settings are about access, confidentiality, consent and privacy, and the expertise and continuity of professionals (RCPCH 2003). McDonagh (2005) highlighted the need for adult physicians to take forward the impetus and enthusiasm of some of the paediatricians in these areas. More recently, McDonagh and Kelly (2007) have argued that transition to adult health care should be seen as a process beginning in paediatric care at 11-12 years and continuing into adult care until adolescent development and transition into independent living and employment are completed.

2.4.2. Transition into employment

Employability is closely linked to educational achievement, thus young people who face serious challenges in attaining educational qualifications are likely to experience difficulties entering employment. Difficulties in entering the labour market increase the risk of social exclusion in socially disadvantaged groups.

Educational achievement

Socioeconomic circumstances form part of the context in which chronically ill young adults move into adulthood, and reaching the end of their formal education is a critical time, in the sense that the relationship between their families' social resources and their own resources changes, as it does for all young adults, to meet the risks and challenges of adult working life (Schoon, McCulloch, Joshi, Wiggins, & Bynner, 2001; Thomson, Bell, Holland et al., 2002; Thomson, Henderson, & Holland, 2003). Social class affects attitudes to educational success, and reportedly induces feelings of inferiority and reduces aspirations in working classes (Reay, 2005).

Protective factors identified included small family size, a well-educated mother, a father who helped with child care, and parental involvement in their children's education (Schoon, McCulloch, Joshi et al., 2001; Schoon & Parsons, 2002). Bagnall et al (2003) suggested, that the greater civic engagement and looser networks made
by mobile middle class parents around voluntary organisations such as the Parent Teachers' Associations, meant their children 'got ahead' educationally, in comparison to less mobile working class parents with tighter networks based on residence, leisure, kith and kin. However, quantitative analysis of 1988 data in the US (Wells, Sandefur, & Hogan, 2004) suggested that many of the socioeconomic resources that middle class families use to support transition, such as their social network capital and cultural capital (Bagnall, Longhurst, & Savage, 2003; Li & Pickles, 2005), have a smaller impact where children have disabilities, and the usual intergenerational transfer of high socioeconomic status does not occur (Blaxter, 2004 (1); Blaxter, 2004 (2); Hills, Brewer, Jenkins, Lister, Lupton, Machin et al., 2010; Wadsworth, 2004; Wilkinson, 2004).

Both physical and mental health problems have been shown to increase the risk of academic failure at secondary school (Needham, Crosnoe, & Muller, 2004), and more specifically, for this study, educational outcomes for those with ERF have been widely reported to be less good than for healthy cohorts in Europe and US (Bartosh, Leversen, Robillard, & Sollinger, 2003; Broyer, Le Bihan, Charbit, Guest, Tete, Gagnadoux et al., 2004; Groothoff, 2004; Groothoff, Cransberg, Offringa, van de Kar, Lilien, Davin et al., 2004; Groothoff, Grootenhuis, Offringa, Stronks, Hutten, & Heymans, 2005; Offna, Latta, Hoyer, Baum, Ehrich, Pichlmayr et al., 1999). Amongst other disease groups, Dyson et al (Dyson, Atkin, Culley, & Dyson, 2007) showed that sickle cell disorders (SCD) affected the educational attainment children in UK schools, and that adolescents with SCD faced opposing demands from health care and school practices at school. They concluded that 'reactions of teachers and peers to sickle cell have the potential to drain the somatic, cultural and social capital of young people living with sickle cell' (Dyson, Atkin, Culley, Dyson, & Evans, 2011 p 465).

Children with disabilities are also at risk of educational underachievement. Wagner and Blackorby (1996) showed how US students with disabilities were more likely to drop out of high school than normal children, and were more likely to be from poorer families. When employed, poorer young adults with disabilities earned less than those with disabilities from wealthier families.

Entering employment
Literacy and numeracy, generally accepted as prerequisites for employment, have been shown to be insufficient on their own (Cieslik & Simpson, 2006), as weaknesses in 'basic skill competencies' are also barriers to education and employment.
Vulnerable unemployed youth were reticent about accessing opportunities; it was not that they could not get a job, but that they decided not to apply in the face of 'relatively meaningless choices between one poor job or training scheme than another' (Cieslik & Simpson, 2006 p 224). Jackson (Jackson, 2009) suggested that some employers perpetuated social stratification by selecting candidates with a combination of personal characteristics, including gender, school, university attended and interests, that were associated with socially elite groups.

Both physical and mental health are important for employment (van der Wel, 2011). Stam et al (Stam, Hartman, Deurloo et al., 2006) showed how young adults with chronic illness were less likely to participate fully in the labour market, and survivors of childhood cancer and ERF were the most adversely affected. A recent European longitudinal comparative study found that ill health in young adulthood led to poorer long-term employment outcomes (van der Wel, 2011), and this was exacerbated by having few educational resources and by limited access to social welfare (van der Wel, Dahl, & Thielen, 2011).

Severe mental illness has, reportedly, an adverse effect on education, employment and economic resources, especially if it begins in adolescence (Nordt, Muller, Rossler, & Lauber, 2007). Williams (Williams, 2000b) drew attention to the role of biographical disruption in the aetiology of chronic illness, especially so-called 'lifestyle' diseases and mental illness. It is now well-established that many young adults, whose primary illness is physical, including ERF, develop mental health problems (Berney-Martinet, Key, Bell, Lépine, Clermont, & Fombonne, 2009; Bullington, Pawola, Walker, Valenta, Briars, & John, 2011; Fukunishi, Sugawara, Takayama, Makuuchi, Kawarasaki, Kita et al., 2002; Vasquez, Valderrabano, Jofre, Fort, Lopez-Gomez, Moreno et al., 2003).

2.4.3. Transition into adult social relationships

In a large multimethod study of marginalised discreditable young adults aged 16-25, Valentine et al (Valentine, Skelton, & Butler, 2002) observed that while school was the main place to meet and make friends, some interviewees were bullied mainly on account of their 'difference'. Social skills developed at school form the basis for future adult relationships, and young adults with ill health in childhood reportedly had more difficulty in making friends and finding partners (Stam, Hartman, Deurloo et al., 2006) than healthy peers. Early difficulties with peers, and fewer employment opportunities, often combined to reduce social network formation, and led to reduced social capital,
as well as creating relative social isolation, and affecting intimate relationships, sexuality and fertility (Atkin & Ahmad, 2001; Grinyer, 2007; Lowton & Gabe, 2003b).

Social isolation resulting from a chronic illness or disability may stem from its invisibility per se and/or its social invisibility (Lonardi, 2007). In some rare diseases like Duchenne Muscular Dystrophy (DMD), CF and ERF, a generation of young adults which used not to survive to adulthood, now survives. Some of these are well known to the general public, but others are relatively 'invisible'. Blum (Blum, 1995) suggested that 'for the first generation of adult survivors with any condition, it is like living on a new frontier ... akin to being an astronaut – both exciting and scary' (p: 4). He observed that the first generation had a higher than average number of mental health problems, many were socially isolated and had less interaction with peers and friends, and, importantly, those with the least visible conditions, and/or those with least severe disabilities, paid the greatest social, psychological and emotional prices (Blum, Garell, Hodgman, & Jorissen, 1993).

Atkin and Ahmad (2000; 2001) found that transition into adult society was made more difficult for young people with SCD because of the widespread ignorance and insensitivity about the condition amongst acquaintances and the wider public. Professionals and prospective employers were reportedly similarly ignorant and unsympathetic. Young adults with SCD experienced double discrimination and discreditation: as disabled people and as black people (in whom SCD occurs more frequently).

Grinyer's (2007) analysis of the impact of biographical disruption on the lives of young adults with cancer (16-26 years) showed that both timing and context were crucial in shaping their experience of the illness. The fact that their lives were in transition to adulthood exacerbated the impact of the illness on their lives. Their reproductivity was compromised by the illness and/or treatment, as was their sense of self, and the development of their own adult identities. She argued that the impact of biographical disruption was far more severe for young adults than for older adults; their adult identities were more fragile, and more likely to become fragmented than those established over many years' life (Grinyer, 2007).

In CF, the average life expectancy is now almost 40 years. Lowton (2004) found that young adults with CF experienced serious constraints in disclosing a serious illness which was visible 'only when they coughed'. Lowton grouped social situations according to the level of risk of serious adverse consequences that concealment or
disclosure presented: the lowest risk, a casual short term social contact, the highest, employment and potential partners (p 176).

DMD becomes increasingly visible with increasing age, and sufferers are confined to a wheel chair in early adulthood. The inability of young men with DMD to engage in paid employment, and deep-rooted attitudes in society to severe disability, exacerbated the material and social isolation they experienced, and they became deeply resigned to their situation and subordinate social position. They came to accept that the margin of society was where they belonged (Gibson, Acquah, & Robinson, 2004; Gibson, Young, Upshur et al., 2007).

Illness-related social isolation, like rural isolation, can possibly be mitigated, to some extent, through investment in newer kinds of social networks such as illness support groups, and social networking and/or illness-focused websites (Sanders & Rogers, 2007). However, while joining an illness support/self-help group offers the individual an opportunity to build social network capital, comparisons with others who are in better or worse situations is not always helpful (Dibb & Yardley, 2006), and many people with chronic illness eschew such groups/sites. For some young adults, illness-related support groups possibly challenge development of a positive adult identity by reinforcing feelings of abnormality, and differences from ‘normal’. For others virtual social capital/networks, such as offered by the internet, may be the only social network resources available to them for acceptance and support (Rich, 2006).

2.4.4. ERF and achievement of adult markers

A significant number of mainly quantitative single centre European and US studies showed that young adult survivors of childhood ERF had poorer outcomes in emerging adulthood than the general population (Bartosh, Levenor, Robillard et al., 2003; Broyer, Le Bihan, Charbit et al., 2004; El-Husseini, Hassan, Sobh et al., 2009; Groothoff, Cransberg, Offringa et al., 2004; Groothoff, Grootenhuis, Offringa et al., 2005; Offna, Latta, Hoyer et al., 1999; Postlethwaite, Eminson, Reynolds, Wood, & Hollis, 1998; Reynolds, Morton, Garralda, & Goh, 1993; Reynolds & Postlethwaite, 1996; Reynolds, Wood, Eminson, & Postlethwaite, 1995):

- fewer were employed; more were unemployed or unable to work, especially those on dialysis; and
- more lived at home; more males lived at home than females;
- fewer were married or living with partners; more females were married;
- fewer had children.
With respect to living arrangements, a recent literature review (Leiter & Waugh, 2009) found that young adults with disabilities were more likely to find that educational, employment and care related constraints made living in the parental home a necessity rather than a choice, which has relevance for dialysis patients.

However, a recent single Swedish study of paediatric renal transplant patients (Karrfelt & Berg, 2007) reported better adult outcomes, and although more patients were unemployed (14% v 5%), in other respects, such as school performance, proportions living in independent accommodation, living with a partner and having children they were similar to the general population.

In terms of reproductivity, more transplanted males were anxious, more experienced pubertal delay and more saw their health as a major obstacle to sexual relationships and satisfaction with their sexual life (El-Husseini, Hassan, Sobh et al., 2009). A US study (Gill, Zalunardo, Rose, & Tonelli, 2009) showed that the pregnancy rate after transplantation was ‘far lower and declined more rapidly than reported in the general American population ... (and) the live birth rate ... declined in parallel with the pregnancy rate’ (Gill, Zalunardo, Rose et al., 2009 p 1541). In addition the proportion of pregnancies ending in a live birth (55%) was far lower than previously reported, most were lost in the first 3 months.

2.4.5. Role of social capital in facilitating youth transition

Blum (1995) found that for those with childhood illness, ‘successful’ adult functioning at 33 years was associated with having a single supportive adult as a young person. The availability of social capital has been shown to affect both the age at which young people leave home and the path they take (Schoeni & Ross, 2005), but there have been different reports of how far higher socioeconomic status in the family mitigates the negative effects of disability (Bagnall, Longhurst, & Savage, 2003; Li & Pickles, 2005; Schoon & Parsons, 2002; Wagner & Blackorby, 1996; Wells, Sandefur, & Hogan, 2004). Recent work has shown that a high level education exerts a buffering effect on the impact of the onset of disability in young adults (Mandemakers & Monden, 2010). This appears to be due not only to cognitive skills and economic achievement, but also to the increase in socio-cultural resources associated with higher levels of education which can then be used to negotiate with health professionals and increase their social networks.
Social network capital, derived from family, community and employment, provides tangible and intangible support, and has been shown to exert positive effects on educational attainment, health and health related behaviours at transition (Frytak, Harley, Finch, Mortimer, & Shanahan, 2003; Harley, 2001). Thomson et al (Thomson, Henderson, & Holland, 2003) suggested that for disadvantaged youth, social mobility was likely to act against social cohesion, by separating young people from an important source of support, whilst Valentine et al (Valentine, Skelton, & Butler, 2002) described how they saw their families as role models and as sources of information and advice for careers and getting a job, and felt vulnerable if cut off from them. In various minority ethnic communities, strong family networks transmit family values, practices, religion, culture and ethnicity, which mitigate some of the effects of social exclusion (Chattoo, Atkin, & McNeish, 2004; Reynolds, 2004). Family and community expectations were reportedly more important in choosing a career for youths among ethnic minority communities than they were for white youth; but some Asian young people were more worried about independence, leaving home, and losing of family support than most white young people (Cassidy, O'Connor, & Dorrer, 2006).

2.4.6. Summary

Together these studies illustrate that achievement of the goals of adulthood is particularly challenging for young adults with chronic illness, and that the challenges they face are in addition to the challenges faced by all young adults, and those they themselves would have faced, due to social and structural constraints, had they not been ill. They highlight the importance of having access to a variety of social resources to support them through transition with chronic illness.

2.5. CHRONIC ILLNESS IN ADULT LIFE

Adulthood has been 'symbolised through ideas of autonomy, self-determination and choice' (Hockey & James, 1993 p3), although often measured by attainment of markers (Arnett, 2001) as discussed in section 2.3 above. In this section, key concepts in the literature relating to chronic illness in mid and later adult life will be discussed.

2.5.1. Biographical disruption

Early research (Bury, 1982; 1991) based on interview data from mature adults, conceptualised the onset of chronic illness as 'biographical disruption', and distinguished between people's understanding of illness in terms of its consequences and its meaning in their lives:
'First, there is the disruption of the taken for granted assumptions and behaviours; the breaching of commonsense boundaries... Second there are more profound disruptions in explanatory systems used by people such that a fundamental rethinking of the person's biography and self-concept is involved... Third there is the response to disruption involving the mobilisation of resources, in facing an altered situation.' (Bury, 1982 p 169-170).

This work, along with much of the early qualitative research involving adults with chronic illness (Charmaz, 1983, 1999, 2002; Conrad, 1990; Corbin & Strauss, 1987; Cornwell, 1984; Gerhardt, 1990b; Radley & Green, 1987; Robinson, 1990; Scambler & Hopkins, 1990), remains important and relevant. 'Biographical disruption' itself is useful both as an analytical concept and in explaining empirical data. However, it has more recently been 'reconceptualised' to include ideas about biographical disruption in the causation of illness, and ideas of biographical continuity or reinforcement (Williams, 2000b). The latter takes account of experiences across the life course, from those who first become ill in infancy or early childhood, and have few memories of their lives before illness, to those who become ill in later in the life course, and carry memories of their previously 'well' lives, including older people whose lives have been repeatedly disrupted by chronic illness, their own, or family members (Pound, Gompertz, & Ebrahim, 1998).

Moreover, biographical disruption resulting from chronic illness might not be as devastating as other major disruptive events in adult life, such as domestic violence and mother-child separation, especially for people already disadvantaged (Ciambrone, 2001; Williams, 2000b), or in children's lives, where a wide range of different events, such as death of a parent or family member, family breakdown, moving home and examination failure (Thomson, Bell, Holland et al., 2002 p 341) can cause serious disruption.

2.5.2. Health uncertainties

Chronic disease in adult life, as in early life, is characterised by present and future uncertainties which act to reduce personal agency and autonomy. Adults have more life experience than most emerging adults, and are usually more aware of the uncertainties inherent in new developments in medicine, which compound general uncertainties about the future, as every medical advance promises a better life/better health (Fox, 1980), but often fails to deliver and/or meet expectations (Crowley-Matoka, 2005). The loss of status of medicine and scientific knowledge has been recognised by Giddens (1991) and others as a feature of 'late modernity', as people have become more aware of the limitations and the uncertainties of scientific
knowledge, and have become more knowledgeable themselves via use of the internet.

Any initial certainties offered by the diagnosis and naming of a chronic disease are often only temporary, and are replaced by others related to its impact on individual and family resources and wider social lives (Bury, 1991; Robinson, 1990). Older adults reportedly tend to focus more on these wider impacts than younger adults, who have more technical needs, focussing more on their personal health and progress (Bury, 1991; Fitzpatrick, Bury, Frank, & Donnelly, 1987). Royer (2000) found that uncertainty about financial concerns, general health problems, and frustration with medical staff, caused more problems for the non-hospitalised chronically ill people in her study than problems related to the illness itself.

In many chronic diseases, sufferers live with the certainty of short lifespan, but uncertainty about the timing of relatively 'imminent' death. Some diseases, like motor neurone disease, are seen as a 'death sentence', and diagnosis means that 'life' is effectively over, resulting in so-called 'biographical abruption' (Locock, Ziebland, & Dumelow, 2009). However, contemplation of death is likely to be experienced differently by mid life or older people than by young adults whose adult lives have barely begun. Several diseases of infancy and early childhood, such as CF and DMD, have a short life expectancy and are terminal in mid life. Young men with DMD, who expect to die in early adulthood, lived every day as if it was the last day, as must all who know they are in the terminal stages of any illness (Gibson, Zitzelsberger, & McKeever, 2009).

Major organ failure is terminal if untreatable or untreated, so that those who experience it have all been close to death. Organ replacement technologies create particular uncertainties, in that 'donated' organs function less well than the 'originals' and life-saving immunosuppressive technologies themselves bring comorbidities, so that the only certainty is eventual organ rejection, and renewed threat of death, or death itself. After kidney failure, for example, people’s lives continually shift between dialysis and transplantation, between peritoneal dialysis and haemodialysis, between being a hospital inpatient, and being at home, described as a 'roller coaster (ride) between sensation, medical interventions and personal experience ... dynamic and continually altering' (Kierans & Maynooth, 2001 p 251).
2.5.3. Constrained agency
Adults in the UK are continually being called upon by the statutory health services to take responsibility for their own health, in part by adopting healthy lifestyles (Calnan, 2004), but chronic illness limits how far individuals are able to assume such responsibilities. Some evidence suggests that belief in the efficacy of adopting behaviours that protect or influence health, can coexist with lack of control over future health outcomes and fatalistic attitudes (Keeley, Wright, & Condit, 2009). Then, adoption of healthy lifestyles, controlling food and alcohol intake, levels of exercise, and avoiding illegal drugs, offer limited agency to those with chronic illness to reduce illness complications or avoid some comorbidities.

In chronic illness, adult patient resistance to medical advice (Koenig, 2011) has been interpreted as a first 'agentic' step in negotiating and working with health professionals to identify an acceptable treatment regime. Other research has suggested that attitudes to illness make a difference to trajectories of the illness. For example, in lupus, a disease of uncertain trajectory and time-span, people whose time perspective was orientated towards the future were reported to be more likely to have better long-term health outcomes (Sundaramurthy, Bush, Neuwelt, & Ward, 2003). In hypertension, African Americans were more present-orientated and thus, reportedly less likely to see themselves at risk of serious consequences, and less likely to take care of themselves, than White Americans who were more future-orientated, suggesting race and culture possibly make a difference (Brown & Segal, 1996).

However, increasingly health service performance and reforms to the health system, have led to a loss of trust in health services and health practitioners (Brown, 2007), and medical uncertainties have led to changes in people's relationships with medicine. At home, outside the medical gaze, some people are choosing to subvert medical technology (including CPD) and use it in their own way to manage chronic illness (Lehoux, Poland, & Daudelin, 2006; Lehoux, Saint-Arnaud, & Richard, 2004; Thorpe, 2009; Williams, 2003b). Others are increasingly turning to alternative medicines and complementary therapies (Thorpe, 2009).

2.5.4. Social participation in adult life
The challenges emerging adults with chronic illness face in participating in adult social life, are illustrated in outcome data for adults with disabilities. Recent UK data show that employment rates for adults with disabilities are half those of people
without disabilities, and that when employed, disabled men had median earnings 20% lower, and disabled women 12% lower, than people without disabilities (Hills, Brewer, Jenkins et al., 2010 p 19-20, 34). Disabled people with low or no qualifications were most strongly affected by poor pay, and there was some evidence that disclosure of disability made people less likely to be called for interview than others with similar qualifications or experience.

Adults with disabilities also had much poorer access to education and employment opportunities than adults without disabilities, and their leisure, social and cultural levels of participation were also reduced, but much less so (ONS, 2010):

- 56% with people with impairments were restricted in the type or amount of paid work they did versus 26% without impairment;
- 17% had restricted access to learning opportunities versus 9%;
- 83% experienced restriction in participation in leisure, social and cultural activities versus 78%;
- 24% experienced restriction to social contact (close contacts) versus 22%.

The statistical relationships between having a limiting longstanding illness (such as cancer, diabetes, epilepsy and heart disease) and unemployment later in life, and how these varied by educational age and life stage, were investigated in a 3-wave longitudinal study (N ca. 30,000)(van der Wel, 2011). This found that early adulthood was a critical life stage where poor health combined with educational disadvantage led to a high risk of long-term unemployment.

### 2.5.5. Social participation with ERF

Few sociological studies have focused on experiences of living with ERF in adulthood, and in this short section, the kind of constraints, and continuing identity struggles that adults experience shed light on the future lives of young adults with ERF.

Very early studies showed that the time spent on dialysis affected the social lives and employment of adults with ERF (Morgan, 1988). Gerhardt (1990 a; 1991) reported that those in the higher social classes were more able to manage their RRT treatment and choices so that they continued to work, whereas those in the lower social classes tended to lose their jobs. For both groups, socio-economic coping and social support were essential in maintaining or regaining so-called 'normal' life.

Crowley-Matoka (2005) found that kidney transplant patients (28M, 22F, aged 17-62) perceived that their illness led to discrimination in employment, and some chose to
hide their health status; others used their social networks to identify sympathetic employers, or got jobs as a favour from friends. Partners' expectations after transplantation were not realised, and marriages often broke up when partners found the sick person was still sick, and they were both 'worn out' with worry and care. Having children was also problematic, but experienced differently by men and women. For men there were issues related to providing for a larger family with children, and for women, issues related to the strain that carrying a foetus imposed on their kidney graft. Finding an intimate partner/new romantic relationship proved difficult, as disclosure of transplanted status to potential partners meant that many decided just to be friends. Thus, disclosure became difficult, so much so that some looked for partners within the transplanted community.

More recently, significant differences in kidney transplantation outcomes have been reported between different socioeconomic and educational classes, and better graft and recipient survival associated with increased educational achievement levels and being in skilled work (Mistretta, Veroux, Grosso, Contarino, Biondi, Giuffrida et al., 2009).

2.6. CONCLUSIONS

This review has focused on how chronological age mediates the experience of chronic illness in different parts of the lifecourse. Chronic illness in early childhood impacts on the whole family as much as on the child, and the family acts to sustain as far as possible a 'normal' childhood. However, social structures (health and education services) treat children with chronic illness differently from their healthy peers, and the children grow up knowing they are different, and with a sense of self derived from the labels given to them by powerful adult figures.

Adolescence is a key period for both physiological development and development of social identity. Chronic illness at this life stage can delay biological, social and emotional maturation, making many affected adolescents feel different from their peers and making it hard for them to engage normally in peer related activities. Participation in 'deviant' behaviours, such as risk-taking using illegal drugs and/or excess alcohol, accepted as 'normal' at this life stage, were especially threatening to 'health' and treatment regimes. Feeling, looking and behaving differently adversely affected identity development.
There is a dearth of youth transition literature on the experiences of young people with chronic illness per se. 'Normal' youth transition into adulthood appears to be slower today for all young people than for previous generations, and their life trajectories more fragmented. Debate about how far these trajectories are determined by individual choice or structurally determined, illustrates tensions between theoretically versus empirically derived concepts, and between quantitative and qualitative findings, in identifying and explaining differences in youth transition trajectories.

For disadvantaged youth, social constraints on their choices in transition have led to their agency being described as 'bounded', and the trajectory of transition being determined more by social structure and social resources than by individual choice. The literature suggests that transition to adulthood with chronic illness or disability is likely to be similarly socially constrained, but with extra constraints due to the uncertainties and severity of the chronic illness or disability, and the degree to which it disrupts normal life. For both, social structure and resources appear more salient in determining their life trajectories than individual choice. In terms of adult outcomes, both groups experienced delayed educational achievement or underachievement, difficulties in finding employment and establishing independent living arrangements, and difficulties with social and intimate relationships.

Social capital and social resources in the families of chronically ill children and emerging adults and those with disabilities are vitally important in mitigating some of the adverse effects of their condition. However, the availability of social network capital in some families with chronically ill or disabled children may be reduced by the pressures of managing the illness, and breakdown of the nuclear family. Social and socioeconomic resources associated with the middle classes usually, but not always, conferred advantages in education, employment and social networks, on young adults in such families.

Quantitative data show that adults with disabilities and long-term limiting health conditions have lower levels of participation in employment, and other areas of adult social life, than those without such impairments. A large body of qualitative research in medical sociology (not reviewed) has explored the subjective experiences of adults living with chronic illness, and its effect on their everyday social lives. Two sociological studies of adults with ERF illustrate how ERF has a particularly detrimental effect on people's ability to work and experience normal adult life, because of the nature and uncertainties of RRT medical technologies.
In summary, the literature suggests that chronological age of onset is vitally important for understanding the lived experience of chronic illness. For those who are first ill when they are children, the legacy of the medicalisation of their childhood illness locates the 'problem' of illness and/or disability in they themselves, and professional ideas of normality serve to make them feel different from 'normal', first as children, then as young people, and then as adults. For many who are ill early in the lifecourse, their illness interferes with 'normal' biological, social and psychological development, and threatens the development of a secure adult identity, and progress towards autonomous adulthood. It affects education, employment and adult social relationships, and these effects are often cumulative. Chronological age is crucial and illness before puberty has the most detrimental effect. In contrast, those who are first ill as mid life or older adults, experience loss of pre-existing adult identities and adult social roles, 'losses' again cumulative. However, for much older people, onset of chronic illness might be seen as inevitable and therefore in a sense 'normal'.

Little adult literature distinguishes between the experiences of those who become ill in adult life and those who become ill in early childhood, in particular the impact of chronic illness on the development of the individual early in the life course. Moreover, although social and family resources are important throughout the life course in managing chronic illness, they play a key role in childhood and emerging adulthood, affecting every area of child development, so that debates about social structure versus agency in determining trajectories of transition into adulthood are especially salient. Implications for this study are discussed in the Way Forward at the end of the Chapter 3.
3. REVIEW OF CHRONIC ILLNESS LITERATURE ON IDENTITY AND EMBODIMENT

Different academic approaches in the sociology of health and illness have led to different conceptualisations of chronic illness experience over time, and some of the most important of these are reviewed in this chapter. Key concepts for this study include normality, identity, and embodiment, and this review will examine how far these capture chronic illness experience in emerging adulthood, especially for those with ERF.

3.1. IDENTITY

3.1.1. High moral status of health
Health is increasingly seen in contemporary societies as a sign of moral worth, distinguishing those who deserve to succeed from those who deserve to fail (Atkin & Ahmad, 2000; 2001; Crooks, Chouinard, & Wilton, 2008). Some have argued that lay concepts of health adapt and change over time and over the life course, so that even as their health changes for the worse, some older adults feel able to continue perceiving themselves as healthy (Grinyer, 2007; Lowton & Gabe, 2003a). Ill health might be seen as normal in old age (Pound, Gompertz, & Ebrahim, 1998), but young people expect to be healthy, and, for them, being healthy and fit is a source of positive self identity.

A claim for moral status as ‘healthy’ when suffering from a chronic illness, whilst highly desirable, is only possible for those whose illness is invisible in everyday social life. Claims of being healthy and/or normal for those whose illness is clearly visible must always be qualified, since the body continues to be regarded as the foundation on which to construct a reliable sense of self.

The ambiguity of chronically ill young adults’ positioning relative to being healthy was explored by Lowton and Gabe (2003a) in interviews with young adults with CF (N=31, aged 18-40). The authors identified four concepts of health for those with CF, health as normal, controllable, distressing and ‘release’, which were cyclical, in that patients moved around the cycle depending on their current state of health. Whilst the concepts of normal, controllable and depressing are self-explanatory, release was used in the sense of ‘recovery’ from the disease after heart-lung transplantation.
3.1.2. Return to normal life

Being a 'normal' individual living a 'normal' life is part of everyday social discourse, and the concept of normality is pervasive in the sociology of chronic illness. It is also pervasive in medical discourse, where it is seen as the goal of treatment or rehabilitation for those who become ill. However, what is understood as 'normal' everyday social life changes over the life course as dominant peer activities change, so that education gradually 'replaces' children's play, employment 'replaces' education, and relationships with friends and partners become more important than relationships with parents.

There is a large and increasing body of psychosocial and health-related behaviour research literature on coping psychologically with chronic illness, and strategies and styles used to manage it (Bury, 1991; Leventhal, Brissette, & Leventhal, 2003). A common thread in all this work is a drive to be 'normal' and the continual identity work needed for individuals to present themselves as 'normal', or as living 'normal lives'. Almost always this depends on finding the balance between complete denial of chronic illness, 'containment' and complete disclosure.

People with invisible diseases such as asthma, diabetes, SCD, ERF, mental illness, HIV, and many more, are able to choose whether to identify themselves as 'normal' or as 'disabled', or otherwise 'abnormal'. For some, 'coming out' has the advantage of being able to claim benefits and/or adaptations at work, and any associated social support, but the drawback of undermining of any moral status derived from presenting as 'normal', and the absence of such social support (Corrigan & Matthews, 2003).

Normal life for children with chronic illness

The need to live a 'normal' life, an ordinary everyday life, has been reported in many studies of children and young adults living with very different long-term chronic diseases, such as asthma (Prout, Hayes, & Gelder, 1999), sickle cell disorders (Atkin & Ahmad, 2001; While & Mullen, 2003), cystic fibrosis (Lowton & Gabe, 2003b; Willis, Miller, & Wyn, 2001), and cancer (Grinyer, 2007). Atkin and Ahmed (Atkin & Ahmad, 2001) found that young people with sickle cell disorders (SCD) constructed their sense of normalcy from being similar to their peers, and separate from their largely invisible illness, but their normalcy was threatened by the seriousness and uncertainties of their condition, and, as they got older, in life transitions, by racist, disablist and/or sexist discrimination (Atkin & Ahmad, 2001 p 1). In CF normalcy was threatened by its 'characteristic' cough (Lowton, 2004).
Few clinical studies with any significant qualitative element have been published on childhood ERF or transplantation, but those that have, have emphasized the importance to the children of living a normal life. Wise (2002) interviewed 9 liver transplant patients of school age, and described how the children strived to live normal lives. They accentuated their 'normal' abilities and attributes, and described their lives full of 'normal' events, minimising their difficulties. A study of young solid organ transplant recipients (N=18, aged 4-18) (Olausson, Utbult, Hansson, Krantz, Brydolf, Lindstrom et al., 2006) found that most thought they lived, or tried to live, normal lives, described as going to school, doing normal activities like running about and playing, and did not want to feel different from their friends. More recently, a hospital-based interview study of transplanted adolescents reported that 'normal' for them meant having the 'same opportunities and potential to achieve as their peers' (Tong, Morton, Howard, McTaggart, & Craig, 2011 p1). Factors which facilitated this were 'developing their own identity, peer acceptance, making medications routine, freedom and energy, and support structures', but barriers came from 'identity crisis, peer rejection, aversion to medications, lifestyle limitations, and fear and uncertainty' (Tong, Morton, Howard et al., p1). However, peer acceptance could involve adopting risky behaviours that were potentially injurious to their health.

Normal life for adults and older adults with chronic illness
Sanderson et al (Sanderson, Calnan, Morris, Richards, & Hewlett, 2011 p 618) identified six typologies of shifting normalities for adults with arthritis, 'disrupted; struggling to maintain; fluctuating; resetting; returning; and continuing normality'. These accommodated changes in normality over time and as their disease progressed. However, in hospital medicine, normal life is much less subtly conceptualised, and has been described 'a set of culturally potent and highly gendered images related to the family' including working and having children (Crowley-Matoka, 2005 p 826). She found that transplanted patients were forced to accept a loss of 'normalcy', in terms of health, employment and reproductivity; and rehabilitation meant carving out an existence in the spaces 'between the roles of 'sick' and 'healthy', dependent patient, and fully contributing family member' (p 830), described as 'persistent liminality' by Navon and Marag (2004). These transplanted patients were less resigned to living at the margins of society than the 'futureless' young men with DMD (Gibson, Young, Upshur et al., 2007; Gibson, Zitzelsberger, & McKeever, 2009).

Kierans (Kierans, 2005; Kierans & Maynooth, 2001) also challenged medical constructions of transplantation as a return to normal life. Transplantation could not
stand out as an autonomous phase of treatment, because it could not be separated from dialysis, and could not be experienced as a ‘return to independence’ or as a ‘gift of life’ (Kierans, 2005 p 341; p354). Dialysis patients looked towards future transplantation, and dialysis was experienced as ‘life on hold’ (p351).

Overall, it appears that working adults with invisible chronic illness are likely to challenge medically-derived concepts of ‘normality’, and extend the concept of ‘normal’ to include, ‘normal for me’ and/or ‘normal for my age’, especially where diseases are invisible. For older adults, it is more ‘normal’ to experience chronic disease and more dynamic concepts of ‘normality’ reflect the shifting of experience between ‘normal as before’ and new ‘normalities’, which are shared by many in their peer group (Pound, Gompertz, & Ebrahim, 1998; Sanderson, Calnan, Morris et al., 2011; Williams, 2000b).

3.1.3. Social interaction and social identity

Identity development has already been described as a key task of adolescence and marker of emerging adulthood (Arnett, 2001), and as a largely self-reflexive process in connection with individualisation theory (Adkins, 2001; Beck, 1992; Giddens, 1991; Melucci, 1996). However, a symbolic interactionist approach sees identity developing through a system of social interactions, in which people’s sense of self is elaborated, transmitted and refined. Goffman (1959) demonstrated how people present themselves to others so that they create the ‘right’ impression, stressing the importance of verbal and non-verbal clues, and how people manipulate interactions with others to present themselves in a good light. Appearance, clothes, sex, gender, age, size and looks etc, as well as manner, were crucially important then, and remain important today, again especially for young people and younger adults. Gregory (2005) drew attention to the importance of the family, describing how ‘personal identity as individual, as gendered, as family, was established and sustained through on-going interaction’ in the family as well as the outside world (p 374).

Stigma and spoiled identity

Goffman’s (Goffman, 1963) classical work described signs of abnormality as stigmata, a stigma being an attribute that was deeply discrediting, ‘a special discrepancy between the virtual and actual social identity’ of an individual’ (p 12). He argued that people with a stigma were likely to be either ‘discreditable’, if their discrepancy was not known or immediately perceivable, or ‘discredited’, if their discrepancy was known or immediately perceivable (p 14). These terms are still used today to describe the stigma associated with feelings of being different from other
people, and are especially useful in thinking about those with a discreditable invisible
illness like ERF. Scambler (Scambler, 2004; 1986) distinguished between 'enacted'
stigma, the experience of being discriminated against, and ‘felt’ stigma, the shame of
being associated with having a disease and/or the fear of being stigmatised. Clark
(1987) observed that discreditation came not only from others’ rejection but also from
an element of self-rejection, due to a failure to meet their own expectations. More
recently, Yang et al (Yang, Kleinman, Link, Phelan, Lee, & Good, 2007) suggested
that stigma was a moral issue with somatic and emotional dimensions, concerned
with 'what is most at stake for actors in the local social world', as much as a social
interpretive or cultural process (p 1524).

The stigma of having a chronic illness has been experienced by research participants
across a wide range of chronic diseases, especially for young adults (Abadia-Barrero &
Castro, 2006; Bloom, Stewart, Johnston, & Banks, 1998; Camp, Finlay, & Lyons,
2002; Carson & Kelnar, 2000; Farrugia, 2009; Joachim & Acorn, 2003; Moses, 2009;
Rich, 2006; Scambler & Hopkins, 1986; Sirey, Bruce, Alexopoulos, Perlck, Raue, &
Steven J. Friedman, 2001; Thorne, Paterson, Acorn, Canam, Joachim, & Jillings,
2002; Williams, 2000a). Charmaz (1983) described how chronically ill people
experienced a 'crumbling away of their former self images without simultaneous
development of equally valued new ones' (p 168), and became acutely sensitive to
possible discreditation in all their social encounters with other people, to the extent of
imagining it existed where it did not.

Dealing with medication, and inherent uncertainty, meant people became afraid to go
out and their lives became more restricted, and thereby more isolated. Taking
medication may itself be seen as stigmatising and shameful, with a negative impact
on identity (Pound, Britten, Morgan, Yardley, Pope, Daker-White et al., 2005).
Charmaz (1983) suggested that for people with ERF on dialysis, a loss of self 'results
not only from the intrusiveness of the treatments in their daily lives, but also derives
from the knowledge that they are dependent on the machine to live' (p173). This high
degree of loss of control meant loss of self. Some research in transplantation has
focused on the uncertainty of identity when body organs are replaced by those of
another individual. Clearly this is most relevant for heart and face transplantation, but
it has been reported within the wider transplantation field (Deguchi, 1999; Edgar,
2009; Summer, Stone, Scott, & Brashers, 2010).
Management of loss of identity
Managing a chronic illness by 'denial' or 'passing' (Goffman, 1963 p58) remains a common coping strategy (Atkin & Ahmad, 2001; Lowton & Gabe, 2003b; Lowton & Gabe, 2003a). Two styles were used by interviewees with CF (Lowton, 2004): 'fraudulence' in claiming to be normal, and simple denial of the disease, especially following transplantation. Lonardi (2007) discussed how 'passing' led to difficulties in finding an acceptable social representation of an invisible illness and a lack of social support. Partial social representation could be achieved by acknowledgment within the family, so that the family cushioned the everyday social impact of the condition, but in a public arena like employment, sufferers were stigmatised and condemned as 'unreliable, lazy and listless'. Their identity was secure in their own homes, but in the wider social world, any claim of positive adult identity was insecure.

Subsequent research in this field has focused on how loss of positive sense of self is managed in a range of chronic illnesses (Aujoulat, Marcolongo, Bonadiman et al., 2008; Galvin, 2005; Mathieson & Stam, 1995; Rich, 2006; Williams, 1984). A process of narrative reconstruction following a diagnosis of chronic illness (Williams, 1984) was helpful for some people in reconciling pre- and post-illness identities (Bury, 1991; Finlay, 2003) but not others, who remained without a secure identity (Aujoulat, Marcolongo, Bonadiman et al., 2008; Little, Jordens, Paul, Montgomery, & Philipson, 1998; Navon & Morag, 2004). Aujoulat et al (Aujoulat, Marcolongo, Bonadiman et al., 2008) argued that identity 'reconstruction' was achieved by 'differentiating self from illness on the one hand, and by integrating illness and illness-driven boundaries as part of a reconciled self on the other hand' (p 1236), so-called 'holding on' and 'letting go'. Navon and Morag (2004) argued that people without a secure identity were 'left' in a liminal state, where they could not construct an alternative self, and saw themselves permanently unclassifiable, without 'cultural scripts for self-classification' (p 2344). For young adults with disability or chronic illness, identity 'reconstruction', for example, based on success in areas where their peer group are successful such as education, employment, sport, body shape, and/or becoming a parent may not be possible for them, as it is for healthier young adults (Fitzgerald & Kirk, 2009; Herndon, 2002; Wilson, 2007).

Employment plays an important positive role in adult identity, and people who are unemployed through ill health lose this basis for self esteem, and the social and psychological support of being in employment, including structured time (Nordt, Muller, Rossler et al., 2007). A study of cancer sufferers (aged 16-35) (Parsons, Eakin, Bell, Franche, & Davis, 2008) showed how reconceptualising work as 'action
with a purpose', and distinguishing between 'illness' work, 'identity' work and 'vocational' work (paid employment) offered sufferers a way of recognising that 'work' did not necessarily have to mean 'vocational'. Instead it could be the kind of everyday work people with a chronic illness did to support and sustain their key identities, and thereby valued. They suggested that patients felt more able to challenge narrow clinical and employer expectations, that a 'return to work' simply meant a return to paid employment. However, a quantitative study of the relationships between participation in work and well being confirmed the positive relationship between life satisfaction and work (van Campen & Cardol, 2009), but found the proportion of 'satisfied people' with work was lower for those with physical disabilities.

3.1.4. Conclusion
The loss of positive identity following onset of chronic illness, the stigma of being, or feeling, different from other people, and the challenges inherent in developing a new positive adult identity in the face of reduced participation in everyday social life, mean that many with chronic illness, especially young and mid life adults, find it difficult to find an 'acceptable' way to reclassify themselves. In these circumstances, claims to be living a 'normal' life and passing for normal, offer those with invisible disease ways of sustaining a positive identity, albeit relatively insecure.

3.2. EMBODIMENT IN CHRONIC ILLNESS

The body, its shape, appearance and physical fitness, is especially important for younger adults, assaulted daily by every kind of media representation of idealised stereotypes of femininity and masculinity (Buckingham, 2009). The media place such a high value on youthfulness and possession of a youthful, slim, and healthy body, that a young, imperfect and unhealthy body is not only potentially rejected by others, it is not willingly accepted as 'self' (Shilling, 2005). Hughes et al (Hughes, Russell, & Paterson, 2005 p12) have argued that there are inherent tensions between the concept of 'youth', signifying beauty, hope, potency, vigour and strength, and the concept of 'disability'. Therefore younger adults with disabilities or chronic illness, whose physical bodies and fitness are compromised, find it difficult to identify with their peers, and become excluded from the prevalent societal culture of choice and consumption (Buckingham, 2009).

Moreover, medical norms have been developed and certain 'body forms' designated socially and medically desirable, so there is peer and professional pressure to
conform to these norms. Some have argued that these pressures have led to aspects of physical appearance, the visible external expression of the body and self, being increasingly manipulated by diet and medical, even surgical interventions, to create a more perfectly presenting self (Ettorre, 1998; Shilling, 2005). Thus differences between the 'natural' body and the social are becoming blurred, as the natural body is not only manipulated and changed by technology, but also by social 'reshaping', which sees the body as inscribed and secured by culture (Shilling, 2005).

3.2.1. Social approaches to disability

For many years the sociological literature on disability ignored the body per se, and focused on the need to address a dominant culture, where the labelling of people with disabilities by health professionals, meant that people with disabilities were seen as 'handicapped' or disabled. This led to some acceptance of what is called the 'social model of disability', in which (in general terms) society is seen as disabling, not people as disabled (Oliver, 1992, 2004). The social model was widely challenged mainly on the grounds that it ignored the role of the body, and the location of disability in the physical body (Conrad, 1990; Humphrey, 1994; Kelly & Field, 1996; Lorella, 2004).

Kelly and Field (1996) argued that the underlying biological and physical manifestations of the disease were central to conceptualising chronic illness, and in sociological literature the concept of 'embodiment' has become widely used to reinforce the importance of the role the physiological body plays in chronic illness. It has also been seen as a weaving together of the body, mind and social realms (Nettleton & Watson, 1998), 'the intertwining of mind and body ... a dynamic interplay - a reciprocity - between the whole person and the external world' (Einstein & Shildrick, 2009 p295; Shildrick, 2004).

De Wolfe (2002) argued that distinctions between disability and chronic illness are unhelpful for people with a contested illness, as they only 'shift the boundaries between social and conceptual exclusion' leaving sick people stigmatised, their 'strengths unrecognized and measures to improve their lives unformulated' (de Wolfe, 2002 p 255). Debate continues in wider society about whether those with chronic ill health are in some way 'disabled', and recent disability legislation (European Union, 2005) has been criticised for focusing too much on providing physical access to work and leisure facilities, and too little on the provision of resources to access work for people whose disability is related to ill health, but has no physical disability component.
3.2.2. Managing the impaired body

Irrespective of how disability and chronic illness are conceptualised, whether people with disabilities and/or chronic illness are accepted as socially competent beings, can depend on both the control and presentation of their body. Much empirical work has focused on how interactions between the impaired self and society are managed in various disease/disabling conditions, including cancer (Frank, 2004; Horlick-Jones, 2011; Lupton, 1998). In diseases whose physicality itself or treatment technology, is particularly obtrusive, like skin disease, ERF, SCD and DMD (Atkin & Ahmad, 2000; Atkin & Ahmad, 2001; Gibson, Young, Upshur et al., 2007), the physicality of the body is a primary concern.

Most chronic diseases share a dependence on life support technologies, ranging from medication to machines, but it has been argued that new technologies only reinforce and 'reproduce boundaries between abled and disabled, and normal and deviant' (Moser, 2006 p 373), creating limits to the 'normalisation' of people with disabilities. Transplantation has been described as a valuable site for exploring the complexities of human embodiment, in so far as medical technologies involving spare body parts, recreate not just the body, but also the sense of self (Kierans & Maynooth, 2001). In ERF, technology replaces the functions of a complex organ that controls not only the excretory pathway, but also the balance of body fluids, blurring the borders of the body and the technology, and creating uncertainty about the reality of the 'new' body (Deguchi, 1999; Lawton, 1998).

Medical interventions that blur cultural boundaries between self/other, male/female and life/death, have been shown to create especial difficulties for patients as they try to rebuild a sense of self and self-worth (Sharp, 1995; Shilling, 2005). Young men with DMD took for granted the complex medical technologies they used, and saw them as part of themselves unless events brought them to the forefront of their minds (Gibson, Young, Upshur et al., 2007). Such 'con-corporation of flesh and machine means that the 'techno-body' is the lived body, both inculcating social structures and expressing bodily styles and practices' (Gibson, Young, Upshur et al., p 510). Kierans and Maynooth (2001) looked at the meaning of the gross changes in body shape that occur in ERF when weight is lost in haemodialysis and put on again between dialyses, or when weight is put on after transplantation and lost again during the first year. They observed that ERF results in extreme cases of altered embodiment, both visceral and hidden, as well as visible, and graphically drew attention to the particular importance of the sentient body in ERF.
‘the gushing of blood within the fistula, the tangibility of the transplanted kidney ... (the dialysis) machine with the body’s internal blood flow turned inside out. Headaches, nausea, loss of memory, blurred vision, loss of appetite, gout, shortness of breath ... a manifold of bodily sensation and imagery’ (Kierans & Maynooth, 2001 p 238-9).

In many chronic illnesses, some body fluids need to be managed lest they offend public sensibilities, and technologies frequently used in ERF, to manage dysfunction of the male urinary system, can lead to discrediting flows of urine. Turner described how ‘fluids flowing from the inside of the body to the outside are regarded as socially dangerous and contaminating’ (Turner, 2003 p 1), and leaks of urine or leaks from stoma are reportedly particularly stigmatising (Brittain & Shaw, 2007; Little, Jordens, Paul et al., 1998).

3.2.3. Gender and embodiment

Gender is crucially important in discussions about embodiment, because men and women experience their bodies in socially and culturally different ways. In young adulthood, women are acutely aware of the advantages of being physically attractive (Lavin & Cash, 2001), and young men experience the need to conform to stereotypes of masculinity, especially in terms of fitness and keeping in shape (Watson, 2000b). Gender is also particularly crucial to the lived experience of chronic illness in emerging adulthood, especially where chronic disease may delay sexual maturity (Rianthavorn, Ettenger, Malekzadeh et al., 2004), or results from a genetic condition in which either or both genders might be infertile (Levine, 2002; Lowton, 2004; Petersen, 2006; Shostak, Zarhin, & Ottman, 2011).

Gendered embodiment has been seen to play an important explanatory role in adherence to treatment (Balfe, 2007; Bell, 2000; Willis, Miller, & Wyn, 2001), and in accounting for the gender differences in morbidity and mortality of young adults with cystic fibrosis (Willis, Miller, & Wyn, 2001). Willis et al argued that the prescription of normative masculinity led to males with CF being more positive about their illness, more engaged in physical activity which made them healthier, and more likely to adhere to treatment. In contrast, the social practices of femininity made females with CF more likely to be passive, keener to want an attractive slender body shape, but less likely to be physically active. Women were more likely to endanger their health by non-adherence and men by social practices of masculinity, such as alcohol abuse. In ERF, young adult transplant patients appeared to conform to this stereotype only in so far as more males practised sport than females (El-Husseini, Hassan, Sobh et al., 2009).
Stereotypes of masculinity meant that men with DMD were judged, categorised and labelled by others in their everyday lives, and they either resisted or copied these categorisations according to their own internalised and culturally determined ways of acting, thinking and feeling (Gibson, Young, Upshur et al., 2007; Gibson, Zitzelsberger, & McKeever, 2009). They demonstrated an ability to accept and reproduce ideas about masculinity by, for example, using the speed, power and manoeuvrability of their wheel chairs to show their driving skills or engage in 'violence'.

In chronic illnesses, such as ERF, where medical technologies contribute to obesity, itself discrediting for women, women may be further discredited by manifestation of female 'pathologies', such as excessive menstrual bleeding or amenorrhea (El-Husseini, Hassan, Sobh et al., 2009; Herndon, 2002; LaRosa, Jorge Baluarte, & Meyers, 2011). More widely, Zitzelberger (2005) described how the bodies of women with disabilities were often seen by others as undesirable and their sexual lives rendered invisible. Shildrick (2004) argued that the disabled woman is not essentially different from any other kind of woman in her sexual needs and desires; she may just need help and support to meet these needs.

3.2.4. Conclusion

The physical body plays an important role in the adult experience of chronic illness. Problems with physical appearance, reproductivity, and dependence on medical technologies (and the intrusion of these into the physical body), were especially unwelcome for young adults at a life stage normally characterised by health, fitness and well being, as their bodies were viscerally, and sometimes visibly, very different from those of 'normal' healthy young adults. Conforming to social practices of masculinity and femininity was very important, but was particularly challenging, because of the salience of the physical body in the development of peer and intimate social relationships, and family life.

3.3. OVERALL CONCLUSIONS

Health enjoys a high moral status in society and the literature illustrates how many individuals, especially young adults, with chronic illness choose to present themselves as living a ‘normal’ life, ‘passing for normal’ with peers and other adults, and deny their illness. ‘Normal’ for young adults with chronic illness meant having the same opportunities and potential to achieve as their peers, developing their own identity, and acceptance by their peers. The identity literature describes how ‘passing
for normal' was difficult to sustain in the face of the risk of accidental disclosure, stigma and discreditation, but constructing another positive, age-appropriate, adult identity, in both social and psychological senses, appeared to be challenging. Success in adult social roles such as employment, relationships and parenthood, or sporting success, was hard to achieve for many with serious chronic illness.

The physical body plays an important role in how individual chronic illnesses are experienced, particularly in young adulthood. For individuals with very visible diseases and disabilities, like DMD, 'passing for normal' was not possible, and many found themselves discredited and marginalised in society. In 'invisible' diseases, like ERF and CF, where the physical body is damaged visibly and functionally, but much of the damage is hidden from view, presentation as 'normal' in everyday social life was reasonably secure. Nevertheless, in 'passing for normal', the 'abnormal' body had to be managed to ensure there was no 'leakage' of discrediting information or phenomena. In intimate relationships, external abnormalities cannot be hidden, and functional impairment must be disclosed, thus gendered aspects of embodiment were crucially important in forming or sustaining adult intimate relationships. For younger adults, the gendered body is especially salient, and for those who were ill before puberty, extra difficulties may derive from the delayed maturation of the sexual body and impaired reproductivity. Young adults with chronic illness still experienced a need to conform to gender expectations and gender roles, even where such practices compromised the management of their disease.

There is some debate in the literature about how far people with chronic illness can be categorised as 'disabled', and whether the challenges faced by people with disabilities are similar to, or different from, those with chronic illness. However, there is a large volume of literature (not reviewed) on disabilities per se, but where research focuses on younger people with physical disabilities, it almost always ignores the 'disablement' of people with invisible chronic illnesses.

In sociology, there has been little theoretical focus on the lived experience of chronic illness in emerging young adulthood, but evidence from the mainly adult literature suggests that conceptually, identity and embodiment will be crucially important in understanding the experiences of young adults with ERF. Development of a positive social identity after puberty has been seen to be crucial to successful transition to adulthood, so at one of the most critical periods in all young people's lives, emerging young adults with chronic illness face numerous challenges related to developing a
positive sense of sense, many of which are related to the embodiment of disease at a life stage in which positive presentation of self and peer acceptance are paramount.

3.4. WAY FORWARD

Conrad (1990) argued in 1990 that there was a need to draw generalisable theories from the wealth of sociological studies of the subjective experiences of people suffering from specific chronic diseases, and bring the associated conceptual ideas into a coherent whole. Pierret (2003), later, reflecting the greater importance being attached to structural factors, suggested that examining the relationship between ill health and socioeconomic factors was not enough, there was a need to construct a theory of illness experience which took into account the 'interrelations, reciprocal effects and feedback between subjectivity, cultural factors and social structure' (Pierret, 2003 p17).

The qualitative literature highlighted important sociological concepts essential to understanding the chronic illness experience, but also an apparent dearth of studies examining the interrelationship between ill health and social factors, outside the huge body of literature on social determinants of health. Equally, there were few studies which examined the salience of age of onset of chronic illness. Methodologically, some literature exists pertaining to the advantages a mixed method approach might offer to medical sociology, in terms of increasing the strength of any findings by triangulating data and enhancing engagement of health professionals. This is reviewed in the next chapter.

The relative invisibility and ‘roller coaster’ uncertainties associated with ERF make it a potential source of rich analytical data from which to generate theory. Existing psychosocial renal literature has focused on the quantitative measurement of the psychosocial outcomes of transplanted patients and standardised quality of life measures, largely ignoring individual subjective experience and sociological approaches to knowledge acquisition. There is scant sociological literature on ERF itself, and the literature on sociology of chronic illness in early adulthood has mainly focused on specific, more socially visible diseases including cancer, asthma, diabetes and epilepsy. In youth transition literature, there is little mention of chronic illness, and the main focus is on transition for normal and socioeconomically disadvantaged youth, especially those with disabilities.
This study aims to gather different kinds of research evidence to explore and explain how far sociological concepts, derived mainly from the experiences of mid life and older adults living with chronic illness and experiences of disadvantaged youth transition, contribute to understanding the lived experience of chronic illness in early adulthood. It focuses on the role played by social and family resources in childhood and emerging adulthood, in determining the life trajectories of young adults affected by a childhood chronic condition, using ERF as an exemplar.
4. METHODOLOGY

4.1. INTRODUCTION

This chapter includes an overview of the study, a survey of the relevant methodological literature, an account of how the study was conducted and analysed, followed by the researcher's reflections on data gathering and analysis. Finally conclusions are drawn about the strengths and limitations of the methodology used and their impact on the findings.

A qualitative research approach initially appeared to be most suitable for a study of young adults with ERF, but preliminary work showed that it was not possible to recruit sufficient numbers of interview subjects (interviewees and parents) by informal routes, and a decision was made to recruit them from respondents to a survey of eligible ERF hospital patients, using a specifically designed survey instrument. The addition of a quantitative element offered the advantage of being able to contextualise the qualitative data with survey data, and thereby contribute to the strength of the findings.

Thus, the arguments in this thesis are supported by data from a mixed methods study of young adults aged 16-30 with end stage renal failure (ERF). Quantitative data were collected by self-completion questionnaire, and qualitative data through face to face or telephone interviews with renal patients and some of their parents. Patient interviewees were recruited from survey respondents, and parents recruited with the interviewees' written-recorded permission.

In essence, this was a substantially qualitative study, but one in which simple frequencies and cross correlations of survey data were used to contextualise and challenge the developing arguments from the qualitative data. The survey also provided data on levels of achievement of adult goals (educational attainment, employment, independent living and partnerships). Challenges to the patient interview data came from their parents' accounts, but these increased understanding of the interviewees' childhood experiences, by bringing parental insight into more private, sensitive areas, where interviewees' accounts were limited, possibly because of social pressures to present themselves positively to the interviewer.
4.1.1. Overview of methodology

Phase 1: Patients' self-completion questionnaires
Questionnaires were sent to all young adults, 16-30 years\(^1\), undergoing renal replacement therapy (RRT) in 14 English NHS hospitals. These collected demographic and attitudinal data about their family and home circumstances, renal history, clinic experience, self-management of their disease, everyday social life, current health and the challenges of living with ERF.

Inclusion criteria for young adults
All young adults between 16 years and 30 years and registered with participating renal units as being on RRT.

Exclusion criteria for young adults
Patients not sufficiently well to participate (N=2), as identified by clinicians.

Phase 2: In depth patient interviews
Forty interviews (60 - 90 minutes) were conducted with patients who entered ERF before they were 20 years old. These explored more fully the issues raised in the questionnaires and focused on their own accounts of their illness, and its meaning for them in emerging adulthood.

Phase 3: In depth parent interviews
Twenty parents and/or guardians were interviewed. Findings from these data were analysed, and provided parental perspectives on the interviewees' childhood experiences, and their own, where appropriate.

4.1.2. Ethical issues and consent

Ethical approval from the Central Office for Research Ethics\(^2\) (COREC, 2005) was essential for work with UK NHS hospital patients. Ethical issues were addressed at the outset of the study, and ethical practice underpinned and informed the whole research process from the provision of all necessary information to participants to allow them to give 'informed consent' to participate in the study, to publication and dissemination of findings.

Research ethics are based on four well known principles: respect for autonomy, beneficence, non-maleficence, and justice (Beauchamp & Childress, 2001). Stringent

\(^1\) All patients on RRT on hospital databases with date of birth on or between 1.1.76 and 31.12. 90.

\(^2\) COREC no longer exists, and arrangements for ethical approval are now administered by the National Patients' Safety Agency.
codes of practice govern the use of hospital patients' data and the involvement of patients in research from which they themselves might not benefit, but which is designed to benefit others in a similar position. The ethical principles and codes of practice were especially important for a study into the private and personal lives of individuals, especially those who are disadvantaged and/or vulnerable.

Gaining informed consent from all participants was both important per se (Duncan, Drew, Hodgson, & Sawyer, 2009; Mason, 2002), and a requirement for NHS and University research approval. Participants needed the mental capacity to give 'informed consent': they had to be given sufficient information, the information needed to be fully understood by them, and their consent freely given (COREC, 2005). Informed consent is discussed fully by Mason (2002: p 80-82) and to a lesser extent by Silverman (2001).

Special ethical arrangements are necessary for research involving children under 16 years (Alderson, 2004), and while this study did not include children, special consideration was given to the youngest interviewees, related to confidentiality and their relative inexperience (Duncan, Drew, Hodgson et al., 2009).

4.2. REVIEW OF RELEVANT METHODOLOGICAL LITERATURE

The methodological literature evidences a wide variety of ontological approaches to understanding the meaning of chronic illness for affected individuals, but privileges none above any other. Sociological chronic illness literature focuses on evaluating the kind of qualitative approaches which dominate the field, and draws attention to the limitations of the realist/positivist more quantitative approaches in studying chronic illness. Youth literature is perhaps more eclectic, and researchers readily adopt and adapt methods from many ontologies, addressing the limitations of these in context.

4.2.1. Developing theory

Mason described three main philosophical positions related to the development of theory through data analysis:

- theory comes first: not derived from the data but formulated in advance and tested by deductive reasoning during the research process;
- theory comes last: derived by inductive reasoning from the data; and finally,
- theory, data generation and data analysis occur simultaneously: by 'abductive reasoning', associated with the interpretive tradition and the process of
'moving between everyday concepts and meanings, lay accounts, and social science explanations' (Mason, 2002 p 180).

Deductive reasoning from theory tends to be associated with a quantitative and positivist approach. Inductive, or abductive, reasoning is generally regarded as most suitable for the qualitative data, but open to challenges with respect to generalisability from positivist researchers. More generalisability may be achieved by 'combining' qualitative research with quantitative data from the same population, by using purposive or theoretical sampling, or by using an analytical model that assumes any case is 'universal' (Silverman, 2000 p 103). However, Mauthner and Doucet (2003) argue that the choice of data gathering and analytical methods depends largely on the researcher who is 'embodied, situated and subjective', and who approaches data gathering and interpretation with existing 'epistemological, ontological and theoretical assumptions', which are likely to be 'inaccessible to readers ... (and) inaccessible to the author herself' (Mauthner & Doucet, p 415, p 425).

4.2.2. Qualitative methodologies

Denzin and Lincoln (2000 p 19) described four interpretive paradigms: positivist and post-positivist, constructivist-interpretive, critical (Marxist, emancipatory) and feminist-post-structural, all of which work within a relativist ontology (assuming multiple constructed realities), interpretive epistemologies (researcher and researched interact and shape one another), and interpretive naturalistic methods. Interpretive approaches include ethnomethodology, phenomenology, critical theory, symbolic interactionism, hermeneutics and structuralism. Methodological debate within and amongst these has focused on three challenges, those of representation, legitimation, and practice, and asks which model and methodology offers the best resolution of these?

However, the choice of how qualitative data is gathered is an area of research discourse (Antaki, Billig, Edwards, & Potter, 2002; Atkinson, 2010; Barbour, 2001; Bury, 2001; Charmaz, 1999; Fielding, 1993a, 1993b; Gerhardt, 1990b; Hok, Wachtler, Falkenberg, & Tishelman, 2007; Riessman, 1990; Robinson, 1990; Thomas, 2010), and in a sense, choosing is not the issue, it is more important to recognise the strengths and weaknesses of the chosen method.

4.2.3. Quantitative methodology

Surveys have been extensively criticised in three main ways: philosophically, technically and politically (de Vaus, 1991 p 7-9). These critiques are well known and not discussed in detail here, except to note that surveys gather information from a
sample of respondents about the same prescribed variables, predominantly predetermined by the researcher/s, and while surveys are useful for measuring beliefs, attitudes and behaviours, they do this out of context, and are rarely seen as useful for elucidating meaning. They rarely establish causation, most measuring only the likelihood of 'events' occurring at the same time (correlation). Where survey questions are structured, they force respondents to choose responses from a restricted number of options, often in a range of 'closed' questions; but such limitations can be addressed by offering spaces for free responses to 'open' questions. It is also important to note that factors such as being in poorer health, having a disability or being 'deviant', reportedly affect responses to health surveys (Etter & Perneger, 1997; Korkeila, Suominen, Ahvenainen, Ojanlatva, Rautava, Helenius et al., 2001).

The kind of quantitative analysis appropriate for survey data depends on the complexity of the data, why they were gathered, and how they will be used. Where, as in this study, quantitative data are used to explain and contextualise qualitative data, measures of frequency distribution of single variables and simple bivariate cross tabulation of relevant dependent and independent variables can be considered adequate. Simple measures of association and significance, available via SPSS software, such as p values, chi squared, and phi, are useful in such situations for establishing the character of any relationship between variables.

4.2.4. Methodological considerations for this study
An early consideration was whether, as positivism contends, there is a reality of illness experience to be captured and understood, or whether as post-positivists argue, reality can never be fully apprehended, only approximated and represented.

Mixed methods
While no methods of examining the world are perfect, adoption of a mixed methods approach offers the opportunity to create a 'collage' of social reality, and draw strength from different ontological perspectives (Denzin & Lincoln, 2000; Pierret, 2003). However, Arksey and Knight (1999 p 31) challenged multimethod approaches because it cannot be assumed that data from different approaches can be integrated. Data collected in one model of social theory and analysed in an appropriate framework, does not necessarily fit with that gathered and analysed within a different model, especially if the models treat social reality as being constructed in different ways, and incorporate different ideas about what constitutes data and evidence. However, these authors and others acknowledge that appropriate use of so-called
'triangulation' can enhance a study (Arksey & Knight, 1999; Gubrium & Holstein, 2002; Mason, 2002).

In an argument for mixed method research, Gerhardt (1990b) recognised that medical knowledge and medical models of health, and sociological knowledge and conceptualizations of health and illness, were different in kind, but suggested that they were complementary rather antagonistic. Others have argued that 'triangulation' and multiple methods can offer a more secure understanding of the research enquiry (Mason, 2002; Silverman, 2000) by increasing its 'rigor, breadth, complexity, richness and depth' (Denzin & Lincoln, 2000 p6). They can increase the validity, and, where congruent, give more confidence in the generalisability of the findings.

More recently, Brannen (2005), drawing on work by Hantrais (1999), specifically pointed out the dangers of isolating qualitative data from their equally important context. She suggests that different research cultures should perhaps be regarded as less important than heretofore, because external pressures for research to have practical application mean that the same kind of research may need to be written up in different ways for different audiences.

'Contextualisation is a critical part of the multimethod study in creating and making sense of data ... qualitative analysis in its emphasis on the textual may be weak in contextualisation, that is in making sense of the data in relation to structural context and particular historical moments' (Brannen, 2005 p 182).

**Patient sampling**

Conrad (1990) raised particular issues with respect to using a sample of hospital patients to study chronic illness. These were related to whether the sample was to be clinically derived, medically referred, originate from self-help groups, or be a self-selected voluntary sample. Each of these has limitations, and different analytical implications, so that if access via clinicians is needed, as in this study, then the project needs to be both useful to them, and to be perceived by them as causing no harm to patients. However, Conrad noted that invitations to participants to take part in research which is supported by clinicians are perceived differently by participants from those where the project is administered independently of hospital staff, an important consideration in analysing the data from this study.

**4.2.5. Gathering interview data**

A decision was made to collect qualitative data for this study by interview, accepting that individuals’ 'knowledge, views, understandings, interpretations, experiences and
interactions are meaningful properties of the social reality' (Mason, 2002 p 63), and that language is a good enough means of capturing people's thoughts, attitudes, and behaviours, and of linking attitudes and behaviours (Deutscher, Pestello, & Pestello, 1993).

Interviews are not normal conversations, and although in-depth, loosely structured forms of interviewing share some characteristics of a normal conversation, interviewing is a skilled task and, in most theoretical models, the interviewer largely remains in control of the dialogue (Fielding, 1993b). Thus, the attributes of the interviewer affect the nature and quality of the data collected, and this relationship has remained a subject of continuing academic interest and intense debate. Equally, the attributes of the interviewee, the interview setting, and all the decisions made about how interviewees are recruited, affect the nature and quality of the data (Riessman, 1987).

One way to address some of these issues is for the researcher to consider reflexively their own entanglement in the research process. This means thinking critically about the whole research process, confronting and challenging in-built assumptions, and recognising how the researcher's experience, thoughts, actions, decisions and omissions shape their research and their findings (Mauthner & Doucet, 2003). In practical terms this means that there should be a valid and strategic rationale for decision-making at all stages in the interview process, whilst recognising that some decisions are necessarily made pragmatically, for example taking into account what is happening during the interview itself (Mason, 2002 p 177).

**Interview design**

In some situations, interviews are standardised and highly structured, but for more qualitative studies in depth interviews, less structured or semistructured interviews are needed. In all cases, questions should be open-ended, neutral, sensitive, and clear to the interviewee. They need to be 'answerable', based on interviewees' behaviour or experience, opinion or belief, feelings, knowledge, sensory experiences, or on demographic details (Fielding, 1993b; Fowler & Mangione, 1990; Judd, Smith, & Kidder, 1991).

**Conducting an interview**

There appears to be very little in the sociological literature about how interviewers learn to interview outside the professional doctor patient consultation or the job interview (Roulston, deMarrais, & Lewis, 2003 p 645). An important skill is the ability
to listen well, at the same time as managing complex tasks related to the topic guide, prompts, tape recorder, time, and responding to the interviewee. The interviewer needs to check constantly that his/her understanding of the question and response coincides with that of the interviewee.

**Recording interview data**
Early research, exploring research participants' orientations to the presence and relevance of recording devices in interviews, showed that recording devices were actually part of the social interaction of the interview, and were helpful in creating useful activities in the interview setting (Cornwell, 1984). More recently, recording devices have been described as challenging the normalcy, naturalness and authenticity of interview data, and as potentially distorting the object of analysis, leading to potentially invalid results (Speer & Hutchby, 2003 p 334).

**Sensitive issues**
Interview and ethnographic research into sensitive areas, such as chronic illness experiences, inevitably means that the conversation is likely to embrace personal and private matters, raising issues that a participant might later regret (Watts, 2008). However, it can be argued that such research is justified by the opportunity it offers to provide, to an outsider, an anonymised account of participants' experiences and thus helps them to gain a better understanding for themselves and contribute to 'helping others'. The objectivity of a research study offers evidence beyond individual experience, and draws attention to important matters that might otherwise be ignored by health care providers.

Early research (Brannen, 1988) suggested that interviews on sensitive subjects should be 'one-off' so that there was little chance of researcher and interviewee meeting again, although many such studies today are longitudinal. She also suggested that if the subject matter was sensitive, it should emerge gradually during the course of the interview rather than being approached at the start. Lee (1993: chapter 6) highlighted the need to be aware of the contradictions, complexity and emotional content of the interviewee accounts, and the possibility of interviewee distress at unintended self-revelation. He explored strategies for dealing with sensitive subjects, emphasising the need to adopt a non-judgmental/non-condemnatory attitude and not show amazement, revulsion or contort the face.

An invitation to tell a story about their health experiences, can offer interviewees the opportunity to transform a largely negative experience into something more positive,
or easier to accept (Shamai, 2003). Birch and Miller (2000) categorised the potential benefits for patients in three domains; firstly, the patient is in the powerful position of holding knowledge wanted by the researcher; secondly, the patient, in relating and reflecting on their story, has an opportunity to reconstruct and experience it from another position and in another context, and introduce new experiences not captured at the time; and thirdly, the interview offers an opportunity for the interviewee to be listened to, understood and accepted. These authors drew parallels between qualitative interviews on sensitive or distressing experiences, and ‘talking therapies’, such as counselling or psychotherapy, but cautioned against believing that ‘a more personal story reveals a more authentic story’ (Birch & Miller, 2000 p 200).

Asking young people with chronic illness sensitive questions needs especial consideration (Duncan, Drew, Hodgson et al., 2009). In a study of young people with cancer (Grinyer, 2007), interviews were carried out on hospital premises, and only those identified by staff as physically and emotionally ‘suitable’ were interviewed. Moreover, parents/relatives were present at more than half (p 269). It is also possible that young adults in face to face interviews might seek to protect themselves from stigmatisation, and provide different data than they might provide in a more ‘anonymous’ telephone interview, or otherwise more anonymously, as has been reported (Cook, 2009; Irvine, 2010; Novick, 2008; Sturges & Hanrahan, 2004).

Co-creation of data
Fontana and Frey (2003) discussed how interview data can be seen as being ‘co-created’ from the interaction between the interviewer and interviewee. Recent understanding of co-creation owes much to conversation analysis, where detailed work on the non-verbal, as well as the verbal, content of interviews has highlighted how researchers produce interactional cues that affect the accounts the interviewees provide. This focus on the interviewer’s contribution can lead to greater insight into how interview talk has been co-produced and managed (Mason, 2002:p5; Rapley, 2001; Roulston, Baker, & Liljestrom, 2001; Silverman, 2001). Thus there is some debate about how much the interviewer should speak, some advocating a minimalist approach with a single opening question asking for a biographical narrative; others advocating an ‘active interview’ strategy (Arksey & Knight, 1999; Hathaway & Atkinson, 2003) where interaction between interviewer and interviewee more closely resembles a normal conversation, with more co-creation of data.
Power relationships, role of confrontation
Brannen (1988) discussed inequality in power relationships between interviewer and interviewee in relation to interviews on sensitive topics, which potentially put the interviewee under pressure from an interviewer, such as a doctor, perceived as more powerful. Other researchers have raised related issues, especially where the interviewees are children and/or young adults (Robinson & Kellett, 2004). Power imbalance can be addressed by some kind of reciprocity (Gubrium & Holstein, 2002) such as providing the interviewee with feedback from the findings.

Establishing rapport and trust are essential for a successful interview, especially on sensitive topics (Roulston, deMarrais, & Lewis, 2003). However, in their study of 'tolerable deviance', Hathaway and Atkinson (2003) advocated beginning an interview in a relaxed style with open and friendly questions, but introducing more critical, sceptical or confrontational questions later in the interview when rapport has been established, and alternating thereafter between establishing rapport and more confrontational tactics (so-called 'good cop, bad cop'). This could be a high risk strategy for vulnerable people with chronic illness, but could be relevant as 'deviance' includes non-compliance with treatment regimes, or lack of honesty about illness status in employment situations.

Cultural differences between interviewer and interviewee
Bias arises from the interviewer's own cultural endowment, as research questions and topics are framed from the researcher's point of view/culture, The language used in interview questions indicates something of the culture and values of the interviewer, and misdirected interview probes and prompting may indicate, inappropriately and inadvertently, the interviewer's own views. Challenges also arise from the vocabulary used and the different meanings given to the same spoken words, as well as non-verbal communication styles in multicultural societies such as the UK today. Interviews with younger adults pose such challenges around the knowledge and use of youth argot.

Some have therefore argued, that there should be a shared culture between interviewer and interviewee so that they can draw on common experiences and languages (Mason, 2002 p 64). However, misrecognition and misunderstanding occur within cultures, as well as between them, and there is a need to use clear English and avoid jargon in all contexts. In chronic illness research, some language differences between the interviewer and interviewee can be addressed where both are able to adopt the language and style of hospital staff in discussing the illness.
experience. This also serves to distance and 'neutralise' difficult experiences, possibly making disclosure easier, but in so doing, negates their emotional dimension.

The professional style and demeanour of the interviewer, their appearance, style of dress, age, gender, ethnicity and culture, are all important in the context of how these are perceived by interviewees (Arksey & Knight, 1999 p 13, p 103). The level of interviewing experience/confidence, interviewing style, and subject knowledge also make a difference. Socioeconomic differences between interviewer and interviewee might mean that relatively poor and dependent interviewees might find it difficult to protect themselves from intrusive questioning by more powerful middle class interviewers (Mason, 2002 p 80).

**Inarticulacy**

It is common for some interviewees to respond to questions with monosyllabic answers as not everyone is comfortable with or used to verbalising their experiences, thoughts and feelings. This is usually addressed by using open questions which offer fewer opportunities for monosyllabic responses. However, shyness itself need not be an obstacle to obtaining good interview data (Blaxter, Hughes, & Tight, 1996; Hammersley & Atkinson, 1983; Have, 1999; Judd, Smith, & Kidder, 1991; Stubbs, 1983), although it can be for adolescents who lack confidence, and might need the kind of extra consideration offered to children (Duncan, Drew, Hodgson et al., 2009; Fraser, Lewis, Ding, Kellett, & Robinson, 2004).

4.2.6. **Qualitative data analysis**

Rapley (2001 p 318) observed that whatever analytical approach to qualitative data is used, no single practice gives ‘better data’ than any other; what is more important, is to discuss the context in which the data were produced and the action or role of the interviewer in generating them. Mauthner and Doucet (2003) looked at the value of the reflexivity in understanding the preconceived ideas and assumptions researchers bring to analysis and interpretation of their data. They suggested a deeper understanding of the researcher’s role in analysis may only come after reflection and after emotional, intellectual and temporal distance from the process. This is particularly important where the researcher has intimate knowledge and experience of the setting, and key analytical considerations for this study are discussed below.
Transcribing and reading interview scripts
The theories and practices of the researcher as transcriber influence interpretation of interview data (Fielding, 1993a; Lapadat & Lindsay, 1999; Mason, 2002). A transcript can be read literally, with an emphasis on textual analysis, the literal form, content, structure, style, the words and language used, the sequencing of the interaction, and the form and structure of the dialogue (Silverman, 2000 p 151). Formal conversation analysis examines people’s methods of producing orderly social interaction, and has a sophisticated set of transcribing rules which allow analysis of sequences of related talk, roles and identities adopted in talk, outcomes such as laughter and so on, as they occur in naturally occurring talk (McLellan, MacQueen, & Neidig, 2003).

Such non-verbal data are then used as potential building blocks for development of theory, so how many are to be captured must be decided at the time of transcription (Rapley, 2001). Laughter should be captured (Grynneryd, 2004) because of its role in presentation of self, coping with stress and tensions between interviewer and interviewee, and its relationships to embarrassment or revelations about sensitive topics. Silences and omissions should also be captured, as silences often indicate where an event, or feelings about an event, has not been related before, or is challenging; ‘omissions’ might indicate where pertinent data are suppressed (Charmaz, 2002).

Narrative accounts of chronic illness
Interviews depend on other people being able to ‘verbalise, interact, conceptualise and remember’ things about their experiences (Scott, 2004). Both the mental and physical health of the interviewee can affect memory recall, resulting in inaccurate recall. Also narratives may be changed by repeated telling of the same story until any sense of the original ‘story’ is lost. This is potentially a particular problem in research into chronic illness, where the ‘story’ might have been told many times for different audiences. Cornwell (1984) found that people provided both ‘public’ and ‘private’ accounts of health and illness: the former, often depersonalised and generalised which affirmed or reproduced the moral order, producing socially ‘acceptable’ accounts; the latter more personal, focused on their experiences, and potentially less socially acceptable. Public accounts were often given in first interviews; private accounts emerged during later interviews when rapport and trust had been established.

West (1990) considered public accounts as having the characteristics of a managed or staged appearance, referring to what interviewees ‘ought’ to think and/or do.
Presentation of self is especially important for young adults with chronic illness, because their position in the life course means that pressure to conform to peer norms is particularly acute, and admission of illness arguably more stigmatising than in later life (Goffman, 1959, 1963; Grinyer, 2007). Thus, it is likely that a young person with chronic illness will provide a 'public account', focused on presenting themselves positively, and denying the seriousness of their illness, rather than 'lose face'.

Approaching the interview as 'narrative' stresses the importance of the 'story the respondent has to tell' (Conrad, 1990 p 1258). Methods of analysing narrative or biographical accounts (written or spoken) have evolved over time as better ways have been sought to interpret and explain narrative texts at different levels (Bury, 2001). Analytical approaches range from the microstructural, in which the 'how' of telling, including linguistic markers such as verb tense, timing, sequencing, is regarded as being as important as the content of what is told (Riessman, 1990), to the macrostructural, in which the whole script is examined in order to identify the different discourses that comprise the accounts, and how these are laminated on one another (Robinson, 1990). Wilkinson (2000) compared content, biographical and discursive analyses of the same interview data in three analytically problematic areas. She concluded that content analysis was most useful for obtaining a summary or overview of the data across cases, but that it was weak on context; that biographical analysis was needed to get a rich account of individuals' lives, but did not offer the breadth of content analysis; and that discursive analysis was able to take some contexts into account, but did not offer a focus on people's lives outside the research context.

In a review of chronic illness narrative research, Bury (Bury, 2001) warned that the 'shaping of narratives by motives and context, may be lost or downplayed if personal accounts are taken only at face value' (p 281). He identified three different forms of patient experience narratives according to the functions they fulfilled, and the ways in which the narrator accounted for him/herself, which could be used for comparison of whole accounts across an interview sample:

- 'contingent narratives' which address beliefs about the origins, the proximate causes of an illness episode, and the immediate effects of illness on everyday life;
- 'moral narratives' that provide accounts of (and help to constitute) changes between the person, the illness and social identity, and which help to restore the moral status of the individual or help maintain social distance; and
‘core narratives’ that reveal connections between the lay person’s experiences and the deeper cultural levels of meaning attached to illness and suffering ...’ (Bury, 2001 p 263).

Grounded theory
Grounded theory allows analysis of the data and interpretation to develop together as data collection proceeds, and data collection then continues until no new analytical concepts arise. Classical grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1990) has been heavily criticised on the grounds of fragmenting the data, divorcing it from both context and individual, failing to acknowledge implicit sociological theories which should guide work at every stage, and offering little on testing theories (Charmaz, 1990; Conrad, 1990; Riessman, 1990). It has since been adapted for use in studies where some sensitising concepts have been developed in advance, and which seek to elucidate individuals’ interpretations and understandings of these, alongside any new concepts that arise (Denzin & Lincoln, 2000 p 3-6). Over time, there has been some confusion about the meaning of the key terms in classical grounded theory, such as category, theory, and saturation, and a simplified outline involving 9 analytical steps is provided by Turner (1981 p 231).

Charmaz (1990; 2000) offers a constructivist approach to grounded theory which assumes that social reality is relative, recognises the co-creation of knowledge by researcher and subject, and aims towards interpretive understandings of subjects’ meanings, by exploring:

(1) Ill people’s creation of taken-for-granted interactions, emotions, definitions, ideas and knowledge about illness and about self, and

(2) Researchers’ sociological constructions which they develop, in turn, by studying chronically ill people’s constructions’ (Charmaz, 1990 p 1161).

4.2.7. Justification for methodological approach used
Different methodological approaches have been discussed above, as have the main considerations for data collection and analysis. The literature suggested that a mixed methods approach is theoretically justifiable for this study, and also offers advantages in terms of presenting findings to a wide range of audiences, including patients with ERF, their carers, and the professional teams who treat them as well as medical sociologists.
4.3. PREPARATION FOR THE STUDY

4.3.1. Introduction

All documentation and research instruments, summarised below, were completed and, where necessary, submitted for ethical approval before work with hospitals began. The study was described in the research protocol, summarised at the beginning of this chapter. A self-completion survey instrument was designed to collect relevant data and identify potential interviewees. Qualitative data were generated by conducting in depth interviews with young adults with ERF and parents, using semistructured research instruments.

- Research protocol (Appendix 2, 13.1)
- Patients' invitation to participate letter (researcher)( Appendix 2, 13.2)
- Patients' invitation letter (NHS consultant)( Appendix 2, 13.3)
- Recruitment advertisement (Appendix 2, 13.4)
- Survey questionnaire (Appendix 2, 13.5)
- Patient information sheet (Appendix 2, 13.6)
- Patient interview topic guide (Appendix 2, 13.7)
- Interviewees' consent for parents to be interviewed (Appendix 2, 13.8)
- Parent interview topic guide (Appendix 2, 13.9)
- Patient consent form (Appendix 2, 13.10)
- Local collaborators' briefing (Appendix 2, 13.11)

4.3.2. Access to participants and recruitment

The total number of young adults in the UK with ERF is very small (N= ca 3000 aged 16-30), and patients are dispersed across a large number of specialist hospital renal units. Initially, a young people's group attached to a national kidney charity (NKF), provided contact details for five pilot interviewees, but further recruitment of interviewees by 'snowballing' from this group proved fruitless, as did attempts at further recruitment via other national kidney support groups.

It was therefore decided to survey all age-eligible patients in sufficient hospitals to provide about 1000 respondents, and allow meaningful statistical analysis, assuming a response rate of 20-30%. This process was expected to generate enough volunteers for interview who met predetermined criteria, with respect to age of onset ERF, gender, treatment modality and ethnicity. An age range of 16-30 years inclusive was selected as most appropriate for the study: 16 years being widely regarded as the beginning of adulthood, and thirty years, a reasonable age at which most young adults might consider themselves to be adults. This age range embraces what is now identified as 'emerging adulthood' (Arnett, 2000, 2004).
4.3.3. Recruitment of hospitals

Initially, 15 English hospitals were chosen for their size (Appendix 3, Table 3), the diversity of the populations they served, and their diversity of service provision: paediatric only, adult dialysis only, adult transplantation and dialysis, and collocated paediatric and adult services. More were in the south east to reduce travel costs, and in other regions, accessibility by public transport was important. Renal units of two hospitals merged during the recruitment period, two withdrew and one new one was recruited. Senior renal consultants in each of the hospitals were approached personally by the researcher by email, and simultaneously provided with copies of the draft COREC protocol and survey instrument. Almost all consultants were previously known to her as fellow members of the UK Transplant Kidney Advisory Group, and all except one provided positive response. Fourteen hospitals eventually participated in the study and were coded anonymously (Appendix 3, Table 3).

4.3.4. Development of research instruments

A list of pertinent research questions and sensitising concepts was drawn up from the sociological, youth transition, and renal research literatures. This was used to develop the first draft of a self-completion questionnaire and an interview topic guide, which were piloted with five young adults with major organ failure (one heart). The survey included both closed and open questions, the latter offering respondents an opportunity to provide richer data in some areas. More sensitive questions were placed towards the end, as recommended by Brannen (1988). The last question invited respondents to provide their name and contact details for interview if they wished, but it could be completed anonymously. Each survey was numbered and marked with a hospital code.

The survey questions provided recipients with an indication of the subjects that might be discussed at the interview, and enabled respondents to anticipate the sensitivity of some of the subject areas, in considering whether to volunteer to be interviewed. The questionnaire was also designed to stand alone in case insufficient numbers of respondents volunteered to be interviewed.

The pilot interviews were transcribed verbatim, and the transcripts used to enrich the topic guide and survey questions. Small changes to the survey were made at this stage and important new interview topics were incorporated into the topic guide. These related to financial resources, having children, internet usage, public understanding of renal disease, religion, exercise/physical fitness. A second draft of
the questionnaire was circulated to professional colleagues and ten patients. Their comments and responses, informed the final self-completion survey instrument (Appendix 2, 13.5), which took about 20 minutes to complete. It collected data on:

- Demographic details,
- Education, employment and income,
- Renal history,
- Sources of support,
- Importance of looking after yourself,
- Everyday social life,
- Renal clinic experience,
- Challenges of living with ERF,
- Current physical and emotional health,
- Visibility of ERF in social world.

The development of patient and parent interview topic guides was informed by research literature, pilot interviews and pilot questionnaire data (Appendix 2, 13.7 and 13.9). The topic guides and prompts were devised to direct responses towards achieving the research aims, as recommended (Mason, 2002 p 69-70).

4.3.5. Ethical approval

COREC process
All study documentation was submitted electronically to COREC for approval. Because the research project was 'non-invasive', the application was reviewed by a single so-designated 'main' ethical committee, MREC, which acted on behalf of all the local (to each hospital) ethical committees. The main questions from MREC (face to face interview with the researcher) related to the collection of sensitive data about patients' incomes, and the 'enthusiastic' style of the patient information. Income data collection was accepted as justifiable in terms of assessing transition into adulthood, and a revised patient information sheet accepted. The study gained COREC approval in November 2005, and ethical approval from Surrey University, based substantially on the COREC documentation, a few weeks later.

Hospital R&D approval
A completed National Research and Development Form was submitted electronically for each participating hospital (N=14), including a named NHS Principal Investigator (PI) for each. The hospital R&D approval process was longer and more protracted than COREC, with several hospitals requiring completion of site-specific R&D forms.
and signatures from senior hospital staff (the PI, head of the renal unit, and business manager). A temporary Honorary Contract for the researcher was needed for each hospital, which meant providing references, sometimes blood tests (for hepatitis) and site-specific Criminal Records Bureau clearance, usually at the enhanced level. No changes to the research protocol or research instruments were requested by hospital staff or made at this stage.

Informed patient consent
The patient information sheet (Appendix 2, 13.6) provided full information about the kind of research being carried out and the risks to the participant (from emotional as well as physical harm). It also provided detailed information about confidentiality: how the data would be captured, how and where it would be stored, who would see it, how it would be used in data analysis, and how it would be published or disseminated. It provided reassurance to participants that their parents would not be interviewed without their own (interviewees') explicit consent, and informed potential interviewees that they could withdraw from the study at any time. It thus became a long, and potentially daunting, document for recipients to read.

Confidentiality
Full details of how confidentiality of individual participants', families' and staff personal details and hospital identities was to be maintained, was required for NHS and University ethical approval. R&D approval at each of the hospital trusts required the involvement of their Data Protection Officer, as well as signing a confidentiality clause in the Honorary Contract. To meet these requirements, all electronic data files were anonymised and password protected, wherever they were stored. The anonymised raw data were allowed to be shared with the researcher's current (and any future) University PhD supervisor.

All interviewees were given fictitious names to preserve their anonymity, and, at no point, in the conduct of the study or in its dissemination, did hospital staff know who had responded to the survey, nor who had been interviewed. Care was taken in dissemination of findings to staff at individual participating hospitals, not to use direct quotations from their own patients which could render them identifiable to the audience.
4.4. QUANTITATIVE DATA COLLECTION AND ANALYSIS

4.4.1. Pilot data collection process

The process of collecting data from hospital patients was expected to be difficult and a local collaborators' briefing sheet was prepared to support this (Appendix 2, 13.11). Different processes were piloted, initially in one, then in four more hospitals early in 2006, after ethical and R&D approvals had been obtained. Full participants' packs (as described in Appendix 2, 13.12) were sent to all young adults on RRT, aged 16-30 inclusive, on hospital patient databases during spring 2006. It was recognised that using letters from the hospital consultant on hospital letter-headed paper were likely to influence who chose to respond (Conrad, 1979), but all consultants considered it necessary for patient reassurance, and thought it would enhance the response rate.

Early response rates (ca 33%) indicated that no further recruitment of hospitals would be needed. Pilot questionnaire data were entered into SPSS, scrutinised, and the survey instrument reviewed. Two questions were added to the list of challenges of having ERF; these were related to body scars and worries about the future (Appendix 2, 13.5, Q9).

4.4.2. Main quantitative data collection

Nine more NHS hospitals approved the study over a period of a year. Data collection proceeded with widely varying degrees of administrative support (Appendix 2, 13.13). Reminder letters and duplicate questionnaires were sent to non-respondents between one and two months after the initial mail out, avoiding public holiday periods. In total, 931 questionnaires were sent to all eligible patients treated at 14 tertiary level renal units across England (incl. 2 paediatric units), between spring 2006 and spring 2007, with a response rate of 32% (N=294), following one reminder letter. Most hospitals provided some anonymised patient data for all survey recipients, but their renal units' ability to provide demographic data varied enormously, and gender and ethnicity data for survey recipients were not provided by every unit. Two pilot survey responses met the selection criteria, and these data were included for analysis in the final data set (N=296).

4.4.3. Quantitative data analysis

Data from the questionnaires were entered onto SPSS and analysed by simple cross tabulation of key variables. Responses to open survey questions were transcribed, then organized using Max QDA2. Data analysis confirmed that the sample of survey respondents was reasonably demographically representative of the hospitals' eligible
patients, although hospital data on the latter was limited to gender and RRT modality, and UK and European populations of young adults with ERF (Table, 4.1).

**Characteristics of study participants**

**Table 4.1 Characteristics of survey respondents and interviewees (survey and interview data)**

<table>
<thead>
<tr>
<th>Attribute (self reported)</th>
<th>Issued survey (N=931)</th>
<th>Survey respondents (N=296)</th>
<th>Patient interviewees (N=40)</th>
<th>Subset survey (N=146)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age on 31.12.2006³</td>
<td>na</td>
<td>25.0 yrs (mode 28)</td>
<td>25.6 yrs (mode 27)</td>
<td>27.2 yrs</td>
</tr>
<tr>
<td>Gender</td>
<td>male</td>
<td>57%</td>
<td>60% (N=24)</td>
<td>50.7%</td>
</tr>
<tr>
<td></td>
<td>female</td>
<td>43%</td>
<td>40% (N=16)</td>
<td>49.3%</td>
</tr>
<tr>
<td>Height (mean)</td>
<td>na</td>
<td>1.67m (N=230)</td>
<td>1.65m (N=33)</td>
<td>1.68m</td>
</tr>
<tr>
<td>Weight (mean)</td>
<td>na</td>
<td>67.2kg (N=258)</td>
<td>67.2kg (N=34)</td>
<td>67.4kg</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>white</td>
<td>na</td>
<td>78.6% (N=34)</td>
<td>79.3%</td>
</tr>
<tr>
<td></td>
<td>black</td>
<td>na</td>
<td>5.1% (N=2)</td>
<td>5.5%</td>
</tr>
<tr>
<td></td>
<td>asian</td>
<td>na</td>
<td>10.5% (N=2)</td>
<td>9.7%</td>
</tr>
<tr>
<td></td>
<td>other</td>
<td>na</td>
<td>5.7% (N=2)</td>
<td>5.5%</td>
</tr>
<tr>
<td>Current RRT</td>
<td>transplant</td>
<td>75</td>
<td>73%</td>
<td>77.4%</td>
</tr>
<tr>
<td></td>
<td>dialysis</td>
<td>25</td>
<td>27%</td>
<td>22.6%</td>
</tr>
<tr>
<td>Age onset of RRT</td>
<td>na</td>
<td>17 yrs (mode 7)</td>
<td>11 yrs (mode 7)</td>
<td>na</td>
</tr>
</tbody>
</table>

(Survey Q 1, 5)

³ Wherever 'age 2006' is used, this is 'age on 31.12.06'
The survey sample was skewed towards older respondents and towards those with late onset RRT (as expected) (Table 4.2).

### Table 4.2 Distribution of survey respondents by age and age RRT

<table>
<thead>
<tr>
<th>Age RRT in years</th>
<th>Age 31.12.06 in years %</th>
<th>Total N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>16-20</td>
<td>21-25</td>
<td>26-30</td>
</tr>
<tr>
<td>0-10</td>
<td>28.6</td>
<td>18.3</td>
<td>14.0</td>
</tr>
<tr>
<td>11-20</td>
<td>71.4</td>
<td>62.0</td>
<td>34.9</td>
</tr>
<tr>
<td>21-30</td>
<td>na</td>
<td>19.7</td>
<td>51.2</td>
</tr>
<tr>
<td>Total N %</td>
<td>49</td>
<td>71</td>
<td>172</td>
</tr>
</tbody>
</table>

(Survey 1, 5b)

**Creation of subset of survey data**

Further data analysis suggested that the age at which respondents began RRT affected measurable outcomes of adulthood, and led to the formulation of the following null hypothesis:

> Patients with early onset ERF (defined as beginning RRT aged under 16 years) have no more difficulty in achieving adult status as measured by education, employment, independent living, and finding a partner (at 23 years or older), than those of an equivalent age with later onset ERF (aged 16 or over).

A subset of the data from survey respondents (N=146, table 4.3) was created to test this hypothesis, and the rationale for how this was characterised is presented in Appendix 2, 13.14.

---

4 All respondents who were under 23 years, and all those 23 or over with unstable modality (N=150, 51% 296) were excluded from the subset.
Table 4.3 Distribution of subset of respondents aged 23 or over with stable health by age onset RRT

<table>
<thead>
<tr>
<th>Respondents in stable health(^5), aged 23 or older 31.12.06</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early onset RRT (under 16 years)</td>
<td>57</td>
<td>39.0</td>
</tr>
<tr>
<td>Late onset RRT (aged 16 and over)</td>
<td>89</td>
<td>61.0</td>
</tr>
<tr>
<td><strong>Total N</strong></td>
<td><strong>146</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

(Survey Q1, 5b, f)

Subset data were analysed by simple cross tabulation of key variables, and for the purposes of significance testing, the older stable RRT age group (RRT aged 16 and over) was considered as a control group.

The full quantitative data analysis, hypothesis testing and the statistical significance of the findings, are not presented in this thesis. Instead survey data from the whole data set, the above subset and the interviewees' themselves have been used, where appropriate, to contextualise the interview data and add strength to the qualitative findings.

Characteristics of interviewees

Data analysis also demonstrated that the patients interviewed were sufficiently representative of survey respondents (Table 4.1). However, their demographic characteristics differed from those of the subset of survey respondents, in that they were younger, more were male, fewer were transplanted and their health was less stable. The sample of interviewees included proportionally more individuals with early diagnosis to allow a focus on the importance of the chronological age of diagnosis (Table 4.4).

\(^5\) Stable health means having had no change in RRT modality for 2 years
Table 4.4 Distribution of interviewees by age and RRT age

<table>
<thead>
<tr>
<th>Age RRT in years</th>
<th>Age end 2006 in years</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>16-20</td>
<td>21-25</td>
</tr>
<tr>
<td>0-5</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>6-10</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>11-15</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>16-20</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>6</td>
<td>9</td>
</tr>
</tbody>
</table>

(Survey Q 1, 5)

Fictitious names were allocated to individual interviewees, preserving their cultural background, wherever possible, and where their verbatim words are used in the analysis chapters, they are described in terms of name, age 2006, age RRT began.

Eight interviewees came from different cultural and/or ethnic backgrounds to the majority of the interviewees (Table 4.5).

Table 4.5 Interviewees' culture and ethnicity

<table>
<thead>
<tr>
<th>Name</th>
<th>Culture/ethnicity</th>
<th>Faith</th>
<th>Interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ajay</td>
<td>Asian</td>
<td>Hindu</td>
<td>Face to face</td>
</tr>
<tr>
<td>Alice</td>
<td>Cyprus</td>
<td>Orthodox Christian</td>
<td>Face to face</td>
</tr>
<tr>
<td>Debra</td>
<td>Mixed race African</td>
<td>n/a</td>
<td>Face to face</td>
</tr>
<tr>
<td>Hanna</td>
<td>Chinese</td>
<td>Christian</td>
<td>Face to face</td>
</tr>
<tr>
<td>Gus</td>
<td>Jewish</td>
<td>Judaism</td>
<td>Face to face</td>
</tr>
<tr>
<td>Raj</td>
<td>Asian</td>
<td>Sikh</td>
<td>Face to face</td>
</tr>
<tr>
<td>Samuel</td>
<td>Black African</td>
<td>Christian</td>
<td>Face to face</td>
</tr>
<tr>
<td>Satish</td>
<td>Asian</td>
<td>Moslem</td>
<td>Face to face</td>
</tr>
</tbody>
</table>

(Survey Q 1, 2 & 5)
Interviewees' self-reported diagnoses are listed in Table 4.6, and the disability status of both survey subset respondents and interviewees provided in Appendix 3, Table 4 and Table 5.

A list of the parents' interviewed is provided in Appendix 3, Table 6. They were identified in quotations by adding M or F to the interviewees' names.
Table 4.6 Interviewees’ self reported diagnosis by name and age RRT

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>RRT</th>
<th>Cause of kidney failure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sara</td>
<td>2</td>
<td>congenital, abnormal kidneys at birth</td>
<td></td>
</tr>
<tr>
<td>Satish</td>
<td>2</td>
<td>congenital renal dysplasia diagnosed at 6 month</td>
<td></td>
</tr>
<tr>
<td>Debra</td>
<td>4</td>
<td>unknown</td>
<td></td>
</tr>
<tr>
<td>Kelly</td>
<td>4</td>
<td>congenital bilateral renal dysplasia</td>
<td></td>
</tr>
<tr>
<td>Ben</td>
<td>5</td>
<td>megacystic megaureter syndrome</td>
<td></td>
</tr>
<tr>
<td>Tristram</td>
<td>5</td>
<td>polycystic kidney disease from birth</td>
<td></td>
</tr>
<tr>
<td>Luther</td>
<td>6</td>
<td>genetic: cystinosis</td>
<td></td>
</tr>
<tr>
<td>Amy</td>
<td>7</td>
<td>genetic: from birth</td>
<td></td>
</tr>
<tr>
<td>Edward</td>
<td>7</td>
<td>nephrotic syndrome</td>
<td></td>
</tr>
<tr>
<td>Kieren</td>
<td>7</td>
<td>dyplasia kidneys from birth</td>
<td></td>
</tr>
<tr>
<td>Oliver</td>
<td>7</td>
<td>unknown: from birth diagnosed at 6 weeks</td>
<td></td>
</tr>
<tr>
<td>Cecile</td>
<td>8</td>
<td>unknown: from birth</td>
<td></td>
</tr>
<tr>
<td>Jon</td>
<td>8</td>
<td>congenital dysplastic kidneys</td>
<td></td>
</tr>
<tr>
<td>Alice</td>
<td>9</td>
<td>ureters damaged at birth</td>
<td></td>
</tr>
<tr>
<td>Eugene</td>
<td>9</td>
<td>unknown: at birth, CKD</td>
<td></td>
</tr>
<tr>
<td>Lucy</td>
<td>9</td>
<td>reflux (back flow of urine)</td>
<td></td>
</tr>
<tr>
<td>Lyn</td>
<td>9</td>
<td>blank</td>
<td></td>
</tr>
<tr>
<td>Petra</td>
<td>9</td>
<td>genetic: cystinosis</td>
<td></td>
</tr>
<tr>
<td>Daniel</td>
<td>10</td>
<td>blank</td>
<td></td>
</tr>
<tr>
<td>Jude</td>
<td>10</td>
<td>genetic: prune belly syndrome</td>
<td></td>
</tr>
<tr>
<td>Marc</td>
<td>10</td>
<td>focal and segmental glomerulosclerosis (FSGS)</td>
<td></td>
</tr>
<tr>
<td>Tanya</td>
<td>11</td>
<td>reflux (back flow of urine)</td>
<td></td>
</tr>
<tr>
<td>Anna</td>
<td>12</td>
<td>reflux (back flow of urine)</td>
<td></td>
</tr>
<tr>
<td>James</td>
<td>12</td>
<td>focal and segmental glomerulosclerosis (FSGS)</td>
<td></td>
</tr>
<tr>
<td>Jerry</td>
<td>12</td>
<td>from birth</td>
<td></td>
</tr>
<tr>
<td>Matt</td>
<td>14</td>
<td>from birth, kidney removed at 14 months</td>
<td></td>
</tr>
<tr>
<td>Carmen</td>
<td>15</td>
<td>CKD undiagnosed</td>
<td></td>
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<tr>
<td>Mario</td>
<td>15</td>
<td>congenital renal dysplasia</td>
<td></td>
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<tr>
<td>Wayne</td>
<td>15</td>
<td>genetic: cystinosis</td>
<td></td>
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<tr>
<td>Marian</td>
<td>16</td>
<td>unknown, but both kidneys scarred</td>
<td></td>
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<tr>
<td>Millie</td>
<td>16</td>
<td>IGA nephropathy</td>
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<td>Raj</td>
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<td>lupus</td>
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<tr>
<td>Ajay</td>
<td>17</td>
<td>posterior urethral valves</td>
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<tr>
<td>Hanna</td>
<td>17</td>
<td>genetic: polycystic kidney disease</td>
<td></td>
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<tr>
<td>Samuel</td>
<td>17</td>
<td>focal and segmental glomerulosclerosis (FSGS)</td>
<td></td>
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<tr>
<td>George</td>
<td>18</td>
<td>reflux (back flow of urine)</td>
<td></td>
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<tr>
<td>Luc</td>
<td>18</td>
<td>IGA nephropathy with scarring</td>
<td></td>
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<tr>
<td>Henry</td>
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<td></td>
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<tr>
<td>Laura</td>
<td>19</td>
<td>unknown: antibodies in blood destroyed kidneys</td>
<td></td>
</tr>
<tr>
<td>Gus</td>
<td>22</td>
<td>membranoproliferative glomerulonephritis (MPGN) Type 1</td>
<td></td>
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</tbody>
</table>

(Survey Q 5c)

6 Some interviewees without a definitive diagnosis were born with scarred dysfunctional kidneys. 'Congenital' in the table means 'present at birth', and genetic means an inherited syndrome.
4.5. QUALITATIVE DATA COLLECTION AND ANALYSIS

4.5.1. Selection of interviewees
The interview sample (N=40) was drawn from survey respondents who began RRT between 0 and 18 years (N=38), and included two pilot interviewees (ERF 19 years). Individuals were chosen from those willing to be interviewed following consideration of their survey responses. They were approached, on an on-going basis, so that a reasonably representative mix of modality, age of beginning RRT, RT history, ethnicity and gender was obtained.

4.5.2. Conducting the interviews
The interviews with young adults were conducted face to face in their own homes (27) or by telephone (13), most lasted between 60 and 90 minutes. For the face to face interviews, the interviewees were alone with the researcher, with one exception, where a partner was present for part of the interview. Telephone interviews were used where interviewees were geographically inaccessible, and with few exceptions, interviewees said they were alone. Before each interview, verbal confirmation that the interviewee was willing to be interviewed was obtained, and reassurance that the interview would be confidential was given. All interviews, except one face to face interview, were recorded (with permission) on audiotape. The status of the tape recording was also discussed at the end with each interviewee; none wanted to retain the tape themselves or wanted it destroyed.

The interviews were semistructured, so that interviewees had opportunities to talk about what had most meaning for them, yet allowed the interviewer to steer the conversation towards preexisting research questions. They were supported by the topic guide (Appendix 2, 13.7), and began with an open neutral question about interviewees' experience of kidney failure. However, many did not know where to begin, and were prompted towards a starting place informed by their questionnaire responses, most often their experiences at school. Sensitive areas, such as mental health and intimate relationships, were raised towards the end of the interview when rapport had been established. Three female interviewees became visibly distressed, but all wished to continue. Full contact details of hospitals' counselling services and/or alternative services were offered to interviewees during, or at the end of, the interview.

At the end of the interview, following thanks and reassurance about confidentiality, permission to interview parents was sought where this was seen as potentially
helpful; not all were asked. Three interviewees (2M, 1F) were unwilling for their parents to be interviewed. Where permission was given, a signed form was obtained at the time, by post, or by email. Where this proved difficult, a taped record of their willingness to give permission, where acceptable, was accepted.

Twenty parents (18F, 2M, pilot 1F) were interviewed either face to face (8: 6F and separated couple), or by telephone (12: 11F, 1M, all main care providers) for 60-90 minutes, and their data recorded, transcribed, and analysed.

4.5.3. Qualitative data analysis

A verbatim transcription of all the interviewees was made by the researcher herself (Lapadat & Lindsay, 1999), including pauses, hesitations, restarts. This included brief notes about the pace of speech, length of silences, laughter, volume, tone, quality and pitch of voice, energy levels, body movements and position, and the use of silence and humour in 'covering' embarrassment around sensitive issues (Charmaz, 2002; Grynneryd, 2004).

Early inspection of the interview scripts at a macrostructural level allowed comparisons of individual interviewees' accounts to be made, in order to reach a 'wider understanding of the contexts and 'vocabulary of motives' in which narrative forms, and thus self-identity, are constructed and employed' (Bury, 2001: p 282). This macro analysis provided a useful first step in considering whether dominant themes in individual accounts were heroic or tragic/sad; and whether they were stable, progressive, or regressive towards achievement of personal goals (Robinson, 1990).

A modified approach to grounded theory (Charmaz, 1990, 2000) was used for in depth data analysis, and MaxQDA2 software used to organise the data. Data were entered and coded using theoretically-derived and data-generated conceptual categories. Concurrent data gathering and data analysis meant both the predetermined and emerging conceptual categories were developed and fully saturated. Data fragments were categorised through active and dialectical interrogation and labelling with suitable codes. Following Charmaz, the analytical process involved four different phases of development in order to refine concepts and devise theoretical frameworks on an on-going basis: 'creating and refining the research and data collection questions, raising terms of (sic) concepts, asking more conceptual questions on a generic level, and making further discoveries and clarifying concepts through writing and rewriting' (Charmaz, 1990 p 1162).
Developing concepts involved examining each data code, and, through constant comparison and interrogation, defining it more precisely, and 'raising' it to the status of a concept. Throughout, emerging conceptual categories were used to shape collection of more data from new interviewees, and inform the selection of new interviewees, in an iterative process. Concepts derived from the data were further developed into conceptual categories with specific properties. These were displayed as matrices as recommended by Miles and Huberman (1994). Cross-case matrices and networks were useful for examining relationships between concepts/categories and clarifying emerging theory, and for characterising the effect of 'chronological age of onset RRT' on their lives.

The qualitative data were examined for consistency with the quantitative data and the data from interviewees' parents. This process allowed theory to be constructed which was grounded in the data but not separated from its context. The rigour of this overall process provided confidence that the theory developed, at least partially, explained the data.

4.6. REFLECTIONS ON DATA GATHERING AND ANALYSIS

4.6.1. Reflections on quantitative data
Approaching research subjects via hospital patient databases and their hospital renal unit consultants is known to be problematic (Conrad, 1990). Concerns about threats to participants' relationship with staff and the need for absolute anonymity were partially addressed by providing subjects with reply paid envelopes with the university address. This measure, and the patient information sheet, made it clear to respondents that identifiable individual data were not going to be seen by/made known to the doctors who cared for them. Use of hospital databases meant that the appropriate chronological 'year endings' had to be used as search terms. Moreover, the date of beginning RRT is a poor measure of serious renal disease, as many who begin RRT have been ill for many years, but it was the only reliable quantitative marker of ERF on the databases.

Administrative challenges in preparing and despatching complete participants' packs meant that slightly different processes were used in each hospital (Appendix 2, 13.12, 13.13), and the researcher could not always be satisfied that every eligible patient had been included. Delays in obtaining survey responses meant that changes were made to the survey only after the recruitment pilots (Appendix 2, 13.12), and
questions relating to body scarring and worries about the future (Appendix 2, 13.5, Q9) reached many fewer recipients (N=212).

Early data analysis suggested that participants' total income ranges would have been more analytically useful than separate earned and unearned income ranges (Appendix 2, 13.5, Q4), which could not usefully be combined. Housing tenure (rented or bought on mortgage) was used as a proxy for social class (Appendix 2, 13.5, Q1), but this was only useful where respondents were still living in the parental home, as many 'normal' young adults live independently in rented accommodation at this stage in the life course.

Almost all of those responding to the questionnaire were well enough to read and complete the questionnaire independently, although in two cases, respondents indicated that their parents had helped them with the reading and writing involved. Some questionnaire responses (N=5) suggested low levels of writing skills, though responses indicated the questions had been understood. A reasonably high degree of literacy was needed to complete the questionnaire, leading to a possible over-representation in the data collected towards the more educated. Older individuals were more numerous amongst the survey respondents, reflecting the increase in prevalence of a disease with low incidence and medium term longevity over time.

4.6.2. Reflections on qualitative data

Process issues
For both ethical and practical reasons, all the interviewees were volunteers. This had the advantage that all participants were willing to be interviewed, and not coerced, but the disadvantage of biasing the study towards those who were confident enough to meet and talk to a stranger, and those who were both physically and mentally sufficiently well at the time of the study. However, volunteers are likely to be 'better educated; of higher social status; more intelligent; in greater need for social approval; more sociable', than non-volunteers (Arksey & Knight, 1999: p58). This suggests that the interviewees' data are under-representative of those who do not fall into these categories, and that findings related to achieving the demographic goals of emerging adulthood are likely to present a more positive picture than is really the case. Interviewees with a high need for social approval are also likely to present themselves more positively than those with less need to do so, and are therefore less likely to reveal the extent of the challenges and difficulties they face.
Older individuals were more numerous amongst survey respondents volunteering to be interviewed (76%): 65% of those aged 16-20, 66% aged 21-25, and 83% aged 26-30 volunteered. Interviews with the youngest participants (aged 16-19) were difficult to obtain, and some who participated were shy and inarticulate. However, what they contributed was useful, as they were at the earliest stages of transition into adulthood.

Volunteers probably entered the interview situation with some expectation that the areas discussed would be similar to those in the survey, and were therefore able to consider beforehand how to present themselves, how much they were prepared to disclose and how they might avoid revealing too much. Those who volunteered were more likely to be psychologically robust enough to present themselves positively without fear of unplanned disclosure and/or discreditation, and more able to manage privacy issues, than those who did not. Information provided afterwards by one interviewee (by email) demonstrated that he had carefully controlled what he disclosed; he received a living donor kidney, a few weeks after his interview, from his ‘girlfriend’ who, in contrast to the many family members he mentioned in this context, he had not mentioned at all.

The interview topic guide meant that the interviewer framed and imposed constraints on the discourse, but in practice it was used mainly as an occasional, or final, check that all areas were covered. Few prompts were needed, over and above ‘where to begin’, except with the youngest interviewees.

There were two cases where interviewees were not alone with the interviewer. In one case, the partner of a newly married male interviewee had silently entered the room behind the interviewer after the interview had begun, to work on a computer. It is possible that he gave an account which was congruent with his presentation of himself to her; he was a very confident interviewee who had enjoyed a successful and eventful life after a third renal transplant. In the other case, a telephone interviewee who had had a stroke called on his mother throughout the interview for help in recalling facts. Other telephone interviewees said they were alone, and there were no indications to the contrary.

Some differences between the accounts derived from face to face and telephone interviews were suggested by the data. Whilst cases were too few and too varied to attach great significance to this, it appeared that different kinds of disclosures on sensitive topics were made in the telephone interviews, as has been reported (Cook,
The telephone interview responses were more similar to the survey responses, that is, frequently more negative, possibly more 'intimate', than the accounts provided in the face to face interviews. The researcher's insider and professional knowledge suggests such presentations of ERF could be truer to their lived experiences, but there are dangers in making such an assumption, or in any assumption that more 'intimate' might mean more 'real' (Birch & Miller, 2000).

**Interviewer and interviewee issues**

All interviewees were used to being 'interviewed' and providing a 'case history' for the many renal physicians they encountered; two interviewees (female) were 'celebrities' with national exposure. One of these did not wish to be recorded, so verbatim notes were made contemporaneously at key points in her account. Otherwise most interviewees behaved as if they were unaware of the tape recorder, as far as could be judged, except two who noticed when the tape needed changing. One interviewee said specifically she did not want to talk about the father of her child, but otherwise questions were answered freely. Silences/pauses were most noticeable when interviewees were embarrassed or caught 'off guard' by a probe.

The interviewer was likely to have been perceived by the interviewees as older, female, white and middle class. Her age separated her from youth culture and her ethnicity from the interviewees from African and Asian diaspora. However, these attributes made her a closer 'fit' to a female physician, nurse or a mother figure, people the interviewees were used to talking to.

A decision was made to disclose to the interviewees that the researcher had family experience of ERF, and handled by saying that 'the researcher had helped to care for someone with renal failure'. This proved useful in establishing rapport, and none asked further questions, but it could be seen as compromising the objectivity of the researcher. An interviewer without knowledge of ERF would have generated very different responses from the interviewees; not least because the language of ERF and its treatment are highly disease-specific and without specialised knowledge there would have been a frequent need to interrupt the flow of the 'conversation' for explanation of treatment-related vocabulary. The data may then have been less 'rich'.

The meanings and choice of words used by both interviewer and interviewee during the interview appeared congruent, and both shared an ability to 'neutralise' sensitive topics through use of medical discourse. This facilitated disclosure on intimate issues,
but may also have acted to suppress the emotional level of interviewees' accounts, as it does in a clinical setting. It was possible that the interviewer's knowledge could have been seen as intimidating by the interviewee, but there was no evidence of this, however, any potential benefits from being an 'acceptable incompetent' (Fielding, 1993a p158) were lost.

The researcher's knowledge, as someone whose family had shared similar experiences, possibly contributed to 'allowing' the most disheartened and depressed interviewees to present themselves less positively. The prior experience of the interviewer helped to create a 'shock-resistant' space where shared understanding and empathy were implicit rather than explicit. Interviewer insider knowledge also proved useful in practice, in identifying omissions/obfuscations in the interviewees' accounts which could be gently probed. On balance, the benefits of self-disclosure appeared to outweigh the drawbacks.

Public accounts
About half of interviewees' accounts could be described as progressive and 'heroic', as stories of triumph over adversity and getting on with 'normal' life; about a quarter might be characterised as stable, and the remainder as angry, tragic or regressive. Most were contingent, revealing the impact of ERF on their everyday lives, and/or moral accounts, in the sense they were aimed at establishing their moral status with the interviewer. The apparent need of most interviewees to present themselves positively to the interviewer meant most provided mainly 'public' accounts of their experiences (Bury, 2001; Cornwell, 1984; Goffman, 1959), which possibly presented some barriers to openness in the interviews. Such 'public accounts' would have been rehearsed by the telling and retelling of their 'story' to a plurality of junior doctors in training, and reflect the dominant clinic culture of putting a 'brave face' on things and presenting RRT, especially transplantation as a success. However, these public accounts were interspersed with 'private accounts', indicated often by tone of voice, body language, laughter and embarrassment, or lengthy silences.

The interviewees were also under pressure from more widespread influences in society, especially amongst adolescents and young adults, to be seen to be achieving accepted goals of adulthood. It is also possible that disclosures related to an interviewee's underachievement with respect to GCSE attainment, employment status, or difficulties in social relationships might have led them to mask 'failure' through positive presentation of self.
Parents' qualitative data
While limited use has been made of parents' accounts in this thesis, these were heavily loaded emotional stories of parents' struggles, worries and concerns, and how they had managed these for themselves, and for their children (so-called emotional labour). They stood in marked contrast to most of interviewees' accounts in this respect. The parents' accounts were more evaluative, most were recalling the past (often more than 10 years ago), and interpreting what it had meant for their lives from that time. Some interviewees were not prepared for their parents to be contacted, they appeared to fear what their parents might say to the researcher, more than any apparent lack of trust in the confidentiality of the data they themselves had provided; this influenced the composition of the parent sample.

4.7. CONCLUSIONS

This was a large and complicated project in which gaining access to a sufficient number of eligible patients (young adults aged 16-30 on RRT, distributed in small numbers across a large number of tertiary UK hospitals) proved very challenging. The following limitations, particularly, need to be taken into consideration in data analysis and discussion of the findings, and in any generalisations from the data that might be made.

- the implications of recruiting participants from a hospital sample and endorsement of the study by NHS consultants;
- the over-representation of older respondents aged 25-30, and likely bias towards those who were more literate, healthier and possibly less worried about presentation of self;
- the influence of the survey questions on respondents' considerations of whether to volunteer to be interviewed, and how these might have affected interviewees' accounts;
- the attributes of the researcher as interviewer, in particular her 'insider knowledge', her age, gender, ethnicity and social class, and how these might have affected interviewees' accounts;
- the co-creation of the interview data, especially in the similarity of the interviewer's and interviewees' use of a renal expert lexicon and;
- epistemological differences between the different data collection methods used and validity of the data generated: survey data, face to face and telephone generated interview data.
5. EXPERIENCES OF RENAL REPLACEMENT THERAPIES: DISPELLING THE MYTHS

5.1. INTRODUCTION

The focus of this first analysis chapter is on the meanings of living with ERF for the interviewees and their families from diagnosis onwards. The chapter begins with a brief description of the societal context in which all of the interviewees spent their formative years, one in which most people they met had no idea about the meaning of ERF. Subsequent analysis chapters will focus on biographical disruption in childhood and adolescence (Chapter 6), employment and social identity in emerging adulthood (Chapter 7) and transition into intimate relationships (Chapter 8).

Tables providing study participants' characteristics and interviewees' clinical diagnoses were provided in Chapter 4, 4.4.3, and interviewees' health histories are summarised in Appendix 3, Table 7.

5.2. SOCIAL REPRESENTATION OF ERF

ERF is almost invisible in society as a disease that affects children and young people, and this invisibility was highly relevant to the everyday social lives of study participants, especially in emerging adulthood. The interview and survey data demonstrate that as young adults entering the wider social world, they found little recognition, knowledge and understanding of ERF, especially how it affects younger people. ERF is simplistically and dichotomously portrayed in the media by imagery of transplantation as life-saving and wonderful, and dialysis as 'living death'. This media representation did not reflect most of interviewees' lived experience of ERF, except those who were newly diagnosed and successfully transplanted (Appendix 3, Table 8, Table 9).

Inaccurate in that people think that once you have a transplant you are fixed for life and you will never need dialysis again. (Amy, transplanted, 24 RRT 7)

They make it sound as if it's all doom and gloom. (Jude, dialysis, 22 RRT 10)

Study participants described how only family and a few close friends really understood what living with ERF meant for them (Appendix 3, Table 10, Table 11), and how they experienced a wide range of responses when they told other people (acquaintances) that they had ERF (Appendix 3, Table 12, Table 13). These ranged from admiration, through shock, curiosity, and incomprehension, to pity. Interview
data illustrated how the interviewees feared inappropriate or unmanageable responses, and disliked being judged; several never told other people.

*It is only really my girlfriend that understands the physical and emotional stress I go through.* (Samuel, 28 RRT 17)

*They don't really understand. I tell them I can't drink a lot, I can't go to the toilet, I can't stay over at their house because I have dialysis. They seem to forget.* (Alice, 24 RRT 9)

*They feel pity. I feel they are cautious of catching something at first, especially cases of the opposite sex.* (Raj, 22 RRT 16)

Hanna drew a distinction between the responses of older adults and those of her peers, observing that it was easier to tell older adults because they were less likely to respond in an upsetting way.

*I don't tell casual acquaintances about my dialysis, as I don't want them to talk about me behind me back... they would probably see me as a terminally ill patient and pile on the sympathy ... With adults, it's a bit better, with more life experience, they probably know what to say and they don't really feel bad, but people my age they probably don't want to know.* (Hanna, 18 RRT 17)

This picture of low societal awareness, perceived inappropriate social representation of ERF, and lack of understanding from people who knew about their illness, suggests that little has changed since the ‘first generation survivors’ of diseases like ERF and CF were described as ‘living on a new frontier’ (Blum, 1995 p 4).

### 5.3. IMPACT OF DIAGNOSIS

The background information necessary to understanding the young adults’ experiences of ERF and RRT was covered in Chapter 1. In summary, living with ERF meant living with the side effects of treatment, the inherent instability of treatment modalities, uncertain outcomes, and certain premature death. After diagnosis, the normal trajectory is emergency HD, longer term PD, transplantation, and eventual return to dialysis and/or retransplantation. Because ERF is often the outcome of another primary disease not a disease itself, some of the study participants, including interviewees, did not have a primary diagnosis, some had inherited conditions, and some had anatomical abnormalities developed in utero, such as ‘plumbing’ abnormalities of the urinogenital system (Chapter 4, Table 4.6).

CKD in children is difficult to diagnose and often missed by primary care physicians, as it has few symptoms. Several interviewees' with childhood CKD were not
diagnosed until the physiological demands on the kidney increased around puberty and they went into ERF.

*My mother was living under the impression that I'd be dead by the time I was 14, because apparently doctors said... I wouldn't make it through puberty. (Henry, 30 RRT 19)*

*I went to the GP, had a blood test ... a week later I get a phone call ... saying you're in end stage renal failure ... I was put on CAPD dialysis. (Anna, 28, RRT 12)*

*I got really tired, just like chronic, so I didn't really notice it that much, then at 17 ... the doctor said, 'You've got to be on dialysis' ... that came like a shock, even though I sort of knew... it was going to happen. (Hanna, 18 RRT 17)*

Interviewees who were diagnosed in early childhood were managed by diet and drugs, so that further deterioration to ERF was delayed. Different aspects of the physical body were salient in CKD from the time interviewees were first ill. For example, James' body was so swollen that it took him and his mother 40 minutes to walk to school, and often within an hour or so, she was called to collect him because he wasn't well. Others with early CKD experienced quite visibly intrusive treatment (nasogastric tubes, gastronomy tubes etc) at a very early age, especially if their appetite was poor.

*The swelling kept coming in the genitals ... by the time we'd walked to school he was swollen... you could guarantee probably by about ... half past 10, he'd had enough ... I'd walk home, I'd just start doing things and I would get a phone call, 'James is really in a lot of pain, can you come and get him?' (MJames, 16 RRT 12, FSGS)*

*I had a gastrostomy in my stomach, but for the first couple of years it was through my nose. That was difficult; obviously ... being a facial thing ... people noticed it straight away. (Wayne, 20 RRT 15, cystinosis)*

Most of the interviewees with early childhood ERF had CKD from birth, but diagnosis still came as a tremendous shock demanding immediate hospital admission. Those who began RRT in the preschool years did not talk about the shock or their early days on RRT, most talked only about later struggles with treatment. However, the parents' data (18 mother, 2 fathers), demonstrated the emotional impact of diagnosis and subsequent disruption to family life.

*It was a great shock ... he was 6 weeks old ... they rushed him off ... (to hospital) ... When my husband and I got there, I'd never been so ... scared in my life... he had at least a dozen doctors round him, a huge great needle in his head where they'd shaved all his hair off, and the Professor came to tell us ... he was holding his own. (MOliver, 26 RRT 7)*

*She was totally symptomless ... we had been querying her growth ... I'd been complaining regularly, asking them to check it, eventually ... they took her blood*
pressure ... and she was in hospital within ... 2 hours ... absolutely terrifying ... it's so fast, you actually are completely unaware of anything other than ... the logistics and the practicalities of trying to get a child into hospital. (MAAnna, 28 RRT12)

Those who were older when they became ill talked quite factually about how they felt just before diagnosis, and most had felt extreme chronic tiredness.

Very very tired ... I was ending up sort of crawling up our stairs at home ... not eating much at all, just a constant feeling of feeling sick all the time, drinking a lot more. (Laura, 30 RRT 19)

Diagnosis meant that the interviewees were given the label 'kidney patient' by NHS staff. This 'shorthand', enabled NHS staff to distinguish one patient group from another, but it meant that 'renal patient' was how the interviewees began to perceive themselves, as they spent much of their childhood in a hospital setting.

5.4. LIVED EXPERIENCE OF DIALYSIS

Most interviewees were stabilised on HD in hospital, put on PD, and sent home until they were transplanted, unless PD proved unsuitable. PD was managed at home, and they or their parents (usually mothers) were trained to manage this. Anxiety and uncertainty were present at every PD exchange because if the drained out fluid was cloudy, interviewees needed to go back to hospital immediately, as cloudiness was an early indication of peritonitis; if this happened on holiday, it necessitated a long journey home. Most interviewees who were ill as children remembered the unpleasantness of some of the dialysis medicines they were 'forced' to take, and the 'difficult for them' restrictions of the dialysis diet. Some also remembered how tired they were a lot of the time.

The interviewees maintained on dialysis as adults had chosen the modality that suited them and their lifestyle. More were on HD than PD, but George was the only one who had been on HD at home. Samuel changed hospitals to get a better chance of a successful transplant, but then dialysis took longer because his new hospital had less efficient HD machines.

The machine (HD) had been going well, but it had been taking it's toll on me the last few years ... I had to have an operation to remove my parathyroids ... the last few years definitely I've been weaker and ... I reckon that up to about 4 years you can get away with (HD), after that it starts to knock on. (George, 29 RRT 18)

(HD) 5 hours, 3 times a week ... hospital X was great for dialysis, but a bit poor on transplantation. Hospital Y is great for transplantation, but not great on dialysis. (Samuel, 28 RRT 17)
Interviewees accumulated fluid between dialysis sessions, and if too much had accumulated, it was dangerous. On HD they described feeling dizzy and/or faint during and after dialysis, often because fluids were being removed ‘too fast’. Sitting or lying down on HD for four hours, often feeling unwell, was not good for some interviewees’ emotional health; Ben talked about tensions and peer unpleasantness on the HD ward, Kieren, about dwelling on a failed relationship he wanted to forget.

The emotional roller-coaster you go through after you finish with someone … I have dialysis 3 times a week and sit there for 4 hours, so the first thing that’s running through my head, is, where usually you can keep yourself occupied and move on (from rejection), your moving on process was a lot slower. (Kieren, 29 RRT 7)

Kids can be cruel and people take the ‘mick’ … bullying … (even) in the renal unit, bullying from other teenagers … patients can be very spiteful and nasty to each other. (Ben, 29 RRT 5)

Lifespan on dialysis was limited for many reasons, susceptibility to infection, risk of cardiac arrest, so-called dialysis dementia, scarring of the peritoneum for PD and exhaustion of access sites for HD. Interviewees said they felt less well on dialysis and if they became ill they went downhill very fast, often needing to become an inpatient for a while.

When you become ill on dialysis, you go down hill really quickly … I know when I’m getting a chest infection, within a day, I’ll be constantly in contact with my GP to try and get … antibiotics and nip it in the bud. I’ve just got over a ‘water infection’ (urinary) … Say I go to dialysis tomorrow, I’m feeling under the weather, during the dialysis I get worse. (Tristram, 29 RRT 5)

5.4.1. Waiting for a kidney transplant and kidney donation

Almost all the interviewees had experienced the uncertainty of waiting for a kidney transplant. Few had spent long on initial dialysis as children (most less than 6 months), and most got a cadaveric kidney quickly or had a kidney donated by a compatible parent.

My kidneys failed when I was four, and I was put on the waiting list … but not for too long … I had my kidney transplant when I was 5, which lasted … I believe 4 1/2 years … I had my next transplant when I was 9. (Debra, 27 RRT 4)

I was only on (CAPD) for 6 weeks, then I got a call saying we’ve got a matching kidney for you, and I went into hospital and had the transplant. (Anna, 28, RRT 12)

However some, but not all, of those with failed transplants, had waited a long time for another transplant; the length of time depended on the level of antibodies left by previous grafts, and their age when needing a second or third graft. The average adult waiting time was three years but this masked a wide range of waiting times from
a few months to 15 or more years, and six interviewees had been on dialysis for more than five years.

We were given hope that he'd get his transplant quite quickly, because he was just under 18 ... but it were 2\frac{1}{2} years, by then we had all reached breaking point. (MLuc, 24 RRT 18)

Those on the cadaveric waiting list described living in constant anxiety, as the whole family waited for the telephone ringing. They had no idea at what time of day or night they might be called for a transplant, and no certainty that, if called, the operation would go ahead. It was therefore difficult to make plans, even go on holiday. There was also a great sense of frustration too, a feeling of 'life on hold', as time went on.

I might go abroad, take myself off the transplant list for a week ... sod's law, I get one that week. (Jude, 22 RRT 10)

On holiday, we had the bleeper ... you sat looking at this thing, hoping it wouldn't go off. (MCarmen, 24 RRT15)

Phone call... Sunday afternoon ... we literally packed up everything and shot down there ... and they said ... 'theatre in a couple of hours' time?'. (FDaniel, 27 RRT 10)

Living parental donation went out of favour in the 1990s, as success rates with cadaveric grafts increased, but was the preferred treatment at the time of the study (as now) because cadaveric kidneys were in such short supply. Several interviewees described how their families were immediately approached about living donation, or the family raised it themselves, but decisions about living donation were not easy. Some interviewees had younger siblings needing a lot of care, so their mothers were not considered initially, and some said their parents had been rejected, often on health grounds. Altogether, parents of about a third of interviewees' had donated a kidney, but some found/were finding the decision very difficult.

I don't what I'm going to do about this live donation thing ...I don't know why, I'd do anything for him, I have sort of given up my life for him, but I just cannot do this one thing ... I can't get down to the weight they want me to be, because I know then I've got no excuse ... but then ... if something happens to Jude, I've got that guilt to carry. (MJude, 22 RRT 10)

For the older interviewees, older siblings were also considered as potential donors, but again, decisions were not necessarily straightforward.

My older brother ... he's very suitable, and he'd be happy ... he's not settled, he said that once he's married and things like that ... but he has to see me being very ill first. (Satish, 28 RRT 2)
Even with live donation, there was no certainty that the transplant would go ahead until the two operations took place (simultaneously). Experiences of donation were varied, and not all parents returned to normal quickly.

My father ... offered. (He) was a perfect match ... so they prepped him, everything, had him down in theatre, and all of a sudden decided, no they wasn’t going to do it ... (they) never really gave a solid explanation to us. (Tristram, 29 RRT 5)

(Father) was 'in' for about a month ... he was just in so much pain, he couldn't get out of bed as quick ... After about a year ... he had another operation because it had turned into a hernia, the actual scar site. (Jerry, 25 RRT 12)

However, living donation removed some of the frustrations and uncertainties of being on the cadaveric waiting list, although not all family members were an excellent match and outcomes were only marginally better. Three interviewees on dialysis were particularly hard to match, and incompatible non-parental family members and/or unrelated partners were being 'worked up' in an experimental treatment programme.

I'm hopefully having another transplant ... my Dad, if he's fit ... this will be the first time it's done in X ... taking out all my T-cells', then waiting ... to ensure that ... the antibody ... doesn't grow back with the kidney. (Edward, 30 RRT 7)

5.5. LIVED EXPERIENCE OF TRANSPLANTATION

5.5.1. The transplant operation and post operative period

Transplantation was a major operation, and for a few hours post-operatively, some interviewees described having 24 hour nursing care. Some interviewees said their grafts started working immediately, and others that they had failed straight away (Alice, Amy, Satish) or in the first few months (Appendix 3, Table 7). Most experienced something in between. Thus the immediate period post-operatively was full of anxiety, would the body reject the kidney, would there be any urine?

Post-transplant have experienced, and still experiencing, a roller-coaster of emotions. Very pleased about the kidney, but confused about the changes and anxious about the future. (Q 10 survey respondent)

It never did work really from day one ... unfortunately, they also passed on the virus (cytomegalovirus) ... it didn’t work for the first couple of weeks, then the virus activated... an amalgamation of problems that just couldn’t be resolved. (George, 29 RRT 18)

7 T cells are blood lymphocytes. There are two kinds of T cells: helper T cells and killer T cells. Helper T cells stimulate the B cells to make antibodies, and help killer cells develop. Killer T cells kill the body's own cells that have been invaded by the viruses or bacteria.
Some interviewees stayed in hospital for some time waiting for the kidney to produce urine, or until they were well enough to go home. Those with early signs of acute transplant rejection were treated immediately with steroids, then with much more aggressive immunosuppressive agents, if steroids were ineffective. All of these greatly increased the risk of infection (and death) by attacking the immune system hard. After acute rejection treatment, most interviewees' grafts ‘recovered’, but for some this meant staying on dialysis for some weeks until the immune system responded to treatment.

5.5.2. Living with a transplant

Interviewees who were recent first-time transplant recipients, and whose total transplantation experience had been positive, were pleased with transplant outcomes, but even when ‘well’, they were on up to 14 kinds of maintenance medication, and described being more tired than their peers. Interviewees knew that if they did not adhere strictly to anti rejection treatment regimes, their own immune system would destroy the graft.

So is it taking pills or is it feeling ill ... and they can say, what about the side effects, but ... if you don't take your pills, you're dead. (Edward, 30 RRT 7)

After ... the transplant, the medication just used to make me tired, and I used to sleep through school. (Eugene, 27 RRT 9)

The immediate visible side-effect of post-transplantation medication was the ‘blowing up’ of the interviewees’ bodies and faces caused by high dose steroids, used with other technologies to combat graft rejection. In the late 1980s and early 90s, a new immunosuppressant, cyclosporine was introduced into the paediatric ‘cocktail’ to reduce rejection. This greatly increased graft survival rates, but interviewees described how unpalatable they found it: ‘disgusting’, oily, necessarily ‘injected’ into milk or fruit juice to make it palatable.

Cyclosporine ... it was pretty, pretty, quite horrible ... (and another) very nasty thick pink medicine of some description I didn’t enjoy much. (Daniel, 27 RRT 10)

Nowadays I can’t drink orange juice, because (of) ... the psychological impact of taking cyclosporine with orange juice. (Anna, 28 RRT 12)

Cyclosporine was bad enough, this was much worse ... like red and very kind of thick and chalky ... another looked like someone had mixed ... glue and some water. (Oliver, 26 RRT 7)
It was the steroids and cyclosporine together that caused most of the undesirable visible and invisible side effects that distressed the interviewees. Some decreased with time, others accumulated. However, it was the hairiness and thickened gums that most interviewees mentioned; the damage cyclosporine caused to the kidney graft was invisible. Several of the most recently transplanted interviewees, or those who were over 16 at first diagnosis, were being treated with tacrolimus, and talked less about side effects than those taking cyclosporine, and could expect fewer longer term ill effects.

Cosmetically, the things that really bothered me were my hair, I had really, really thick hair, my gums grew down a lot and I wore braces at the time, and it just ... made it really difficult. (Anna, 28 RRT 12)

My eyebrows became really thick, and then you get like hair round the earlobes and ... my hair on my head became really thin as well ... and it's stayed like that. (Ajay, 28 RRT 17)

I used to suffer hair loss as well ... that was a terrible thing. (Sara, 27 RRT2)

The longer term serious side effects of ERF and/or RRT, such as heart disease, bone thinning and cancer, including skin cancer (resulting from over exposure to strong sunlight), were mostly 'invisible' and symptomless. Several early onset interviewees had been shocked by further related serious illness, four had cancer, but minimised its impact.

I was diagnosed with testicular cancer ... which was a bit of a shock ... I had the tumour removed. Luckily, I was not given any treatment and now they just seem to be keeping a close eye on me. That was a very quick thing ... just a little mishap in life. (Wayne, 20 RRT 15)

You're more aware of how serious it is at different times, like when you're spewing bile and having your heart re-started, than you are when you're sitting here chatting away. (Daniel, 27 RRT 10)

When I first had transplant ... I was very competitive... I played for the school team. I fractured (my wrist)... It keeps reoccurring... your bones are more susceptible to ... injuries and stuff. (Tristram, 29 RRT 5)

All the interviewees knew their grafts were slowly deteriorating due to chronic rejection, and/or the cytotoxic effects of the immunosuppressants. Their maintenance therapy was 'boosted' from time to time if their blood 'creatinine', the marker of rejection rose, and/or if rejection was confirmed by kidney biopsy. Kidney biopsies were frequently needed and routine for the doctors, but interviewees' experiences were often unpleasant.
They seem to do biopsies very, very swiftly, because they’re relatively low risk, but they’re not risk free, they could be shutting down the kidney to find out something that actually didn’t matter that much. (Daniel, 27 RRT 10)

I don’t know whether they’d got a trainee doctor or something to do it … basically they couldn’t get the needle in to the kidney, in the end they brought in one of the doctors I knew who was like a 15 stone rugby player, and he was leaning on it with all of his weight, trying to get the needle into the kidney, and even he couldn’t … they were at it for about 20 minutes, wiggling the needle round, sticking more lignocaine in … yea, it kind of put me off. (Jerry, 25 RRT 12)

The timescale of the deterioration depended on how many rejection episodes the transplanted interviewees had suffered and how severe they had been. Irrespective of how long they had been transplanted (range 0-17 years), almost all (and their families) lived in fear of transplant failure and long-term dialysis.

It’s 16 years (since) I gave Tanya my kidney … Now, it’s at the back of my mind … the thought of her having to go back on dialysis and … wait for a kidney … There’s such a massive waiting list, it fills me with horror. (MTanya, 28 RRT 11)

I don’t know if other mothers are like me, but every time she says she’s got a headache … pains in her back, I always think the worst … At some point, this kidney is going to fail … you want it to last a long time, but at the back of your mind, you’re waiting for it … it’s like a time bomb waiting to go off. (MMarian, 19 RRT 16)

Anna had recently been told that her first transplant of 16 years duration, was beginning to fail. She (below) catches the understated tone of many other interviewees, describing events, which were extremely worrying, invasive and unpleasant, as 'interesting', but her use of the phrase 'the first time' neglects to mention the challenges of managing her medication in her professional life, which involved overseas travel to countries where it was not easily obtainable.

This time last year … my creatinine had gone up … so they ran tests, did ultrasounds and … and biopsy after biopsy … putting it down to wear and tear … they started planning for 2nd transplants and tissue typing my family … (Now) it’s all stabilised again … but that’s been interesting, because it’s the first time in my adult life … that this (transplant) has ever been a part of anything I’ve had to deal with. (Anna, 28 RRT 12)

For most interviewees, transplantation did not fulfil its promise of a return to health and ‘normal life’, and 24 had already experienced graft loss, some more than twice (Appendix 3, Table 7). Sara was too young, at two, to remember how ill she felt when she was first ill, and didn’t realise the significance of her early symptoms of transplant failure when she was 25.
I didn't think I was that ill ... I'd started getting ... quite tired ... and lethargic and I couldn't eat very much, and things like that, though I felt well in myself. (Sara, 27 RRT 2)

Diagnosed with ... renal complications at 6 months ... When I was about 7, I went into complete renal failure ... spent 4 or so years on dialysis, had my Mum's kidney ... which lasted 6 months, put back onto dialysis, in hospital aged 10, for 10 months ... had a kidney transplant ... left hospital, 6 weeks later and stayed out of hospital pretty much for ... 15 years ... Went back into renal failure ... on haemodialysis now, had 35 operations during my life. (Edward, 30 RRT 7)

Daniel was facing the loss of his third kidney (from his father), and his younger sister had recently been diagnosed with renal failure. Their mother was being worked up as a donor for his sister.

(My sister) can see how well you can be after the transplant, but ... she's aware that the second one nearly did for me ... but I'm almost envious of her situation, 'cos instead of being about to have one transplant at 20-something in 2006, I'm looking at a failing third in 2006. I'd rather (be) finding out now I've got renal failure, as opposed to having dealt with it for ... more than 15 years ... She's going into (it) with ... the knowledge as it is now. (Daniel, 27 RRT 10)

Graft loss was a 'catastrophic' event for interviewees and their families, sometimes exacerbated psychologically, if it was parental kidney. For their team of nephrologists and surgeons, it also represented a loss of a precious NHS 'resource', and raised issues of non-compliance. The interviewees went back onto dialysis, and this involved access surgery, less risky than transplant surgery, but still with risks of infection and complications. Socially, it meant a loss of their existing social life, disruption of education, employment and/or social relationships, and dependence on a 'machine' rather than medication.

5.5.3. Sensitisation and re transplantation

The interviewees who had lost one or more kidney grafts experienced new worries each time about the chances of success of any new one, about the length of time they might have to spend on dialysis whilst on the cadaveric waiting list, and about pressures on their family to donate. The antibodies left behind by failed kidney grafts remained in the blood and threatened the success of any new kidney graft. Each graft 'used up' some of the surgical options with respect to where a new graft might be inserted and 'connected up'. Interviewees like Daniel and Satish, who 'needed to know' had been told that that 'as a rule' three transplants was the 'maximum', and knew that they were running out of choices.

He's got loads of antibodies ... he's been waiting what 4 years now. (MJude, 22 RRT 10, 1x Tx)
The first ... although it only went into her for 24 hours, it still left her with antibodies... (her next) will be her 3rd transplant, even though, to me she only had one. (MAlice, 24 RRT 9, 2xTx)

I had the new (kidney), it instantly ... went on the war path ... I had to go through 3 or 4 weeks' process, of cleaning the plasma ... where they take your own plasma out ... put it back in ... just to get rid of the antibodies. (George, 29 RRT 18, 2xTx)

I’ve built up that many antibodies... they’re saying the ideal donor will be someone in your family. (Satish, 28 RRT 2, 3xTx)

5.6. FEARS FOR THE FUTURE

For the interviewees who were transplanted as children, the fears of the medical staff that they would reject treatment, lose their transplanted kidney, then become terminally ill again, were transmitted to them and their parents. Some parents became afraid of letting their children mix with peers who had everyday infections or take everyday risks. Oliver’s mother became so fearful that she decided on home schooling for him and his sister. This decision, though well intended, had devastating unintended consequences for Oliver as a young man. He was completely socially isolated, had never attended school and had no qualifications; he had no friends, was unemployed and lived at home with his (single) mother in a tiny village: no car, no transport, and not even able to ride a bike.

They warned me, ‘As soon as your daughter... starts school, she will bring back everything to him, and he’s going (to go) lower in his kidney function, and he will be in hospital more and more. And just when she would have needed Mummy, Mummy wouldn’t have been there, Mum would be ... with him’. (M Oliver, 26 RRT 7)

Such worries about risks affected all families, but most less severely. Parental 'over-protection' was seen as a 'nuisance' by the interviewees themselves, and in adolescence it also became problematic for NHS staff.

My family hated me taking risks, whether it was football at school or play fighting with my brother, so I had to stop that ... I go up the ladder, and my Mum’s ... ‘Let your brother go up’. (Matthew 24, RRT 14)

Fears for the future were not confined to the earliest onset interviewees, and fears grew following adverse experiences, especially losing a transplant. Those who were ill at junior school were largely reassured by the positive messages they got from consultant nephrologists, but with increasing age, they acquired both knowledge and experience that made them more fearful. Some interviewees had already been in intensive care and near death.
(In) the theatre, the anaesthetist said to my Mother, ‘You do know he’s not going to live don’t you?’ ... (doctor) didn’t recognise me I was so swollen ... I was in intensive care. (Henry, 30 RRT 19)

I remember waking up in intensive care ... being taken down to the HDU, then ... a normal ward ... for further like physio ... ‘cos I couldn’t walk straight for a good few weeks ... It took me nearly a full year to get over it. (Jon, 27 RRT 8)

Few interviewees mentioned death at all, and most who did were graduates. They managed to present death with a level of objectivity similar to that of the health professionals who treated them. Two males talked directly about their own possible death, two females referred to it obliquely, and one more emotionally.

The group of kids that I was with ... (in paediatric hospital), I think I’m the only one left alive, which is a fairly sobering thought. (Anna, 28 RRT 12)

The big thing about renal ... you accept that you’re going to die. You accept that at such an early age that ... it’s a very different dynamic. You can’t explain that to people ... ‘cos they don’t understand it. (Edward, 30 RRT 7)

The fear I have is ... the mortality rate ... The dialysis machine is not great ... you are putting your body under tremendous strain and stress, and it isn’t surprising that so many dialysis patients die of cardiac arrest. (Samuel, 2, RRT 17)

Like the whole ... being ill in the future, I just completely think I’ve got this invincibility feeling, like I just think it would be so unfair if ... anything happened. (Tanya, 28 RRT 11)

I thought it’s better for (my daughter) growing up with her Mum (alive) ... than saying, ‘Where’s my Mum?’ (if I have) another baby. (Petra, 30 RRT 9)

Abnormal body sensations made some afraid. Whilst ERF/RRT is relatively pain free, small everyday bodily sensations dismissed by others, could be a source of private worry, the ‘small beginnings’ of something more serious such as cancer or heart disease.

I worry ... I could be ill again at any given moment, really ... I do get a fear ... if I’ve got a twinge in my kidney. (Tanya, 28 RRT 11)

Dizziness and stuff at home ... the light-headedness and stuff ... I get paranoid that my heart might not be as clever as what it should be, because I have put it under a lot of stress. (Kieren, 29 RRT 7)

5.7. SUMMARY

The lives of the interviewees were characterised by the invisibility, as well as the uncertainties of RRT, and by being subjected to especially invasive medical technologies, including frequent surgery, some of which carried a high risk of mortality. After the immediate impact of diagnosis, each subsequent change of RRT
modality was disruptive, necessitating physiological, social and emotional adjustment. Transplant loss, and repeated transplant loss, made it progressively more difficult to find another 'compatible' kidney, put more pressure on families to donate, and, each time the chances of success were reduced by the antibodies left behind by the first and subsequent grafts. Other problems for interviewees after diagnosis came not only from the disease itself and associated technologies, side effects and comorbidities, but from the way the professional staff managed their condition and the ways that their parents protected them.

The reality of living with RRT early in the lifecourse has been shown to be more complex than the simple picture portrayed in the media and widely accepted by the public. Outcomes of RRT are uncertain; all that is certain is an eventual change/s of RRT modality and early death. What is rarely recognised, and rarely voiced, even by the interviewees, is that most people on RRT live in fear, if not of death, then of being 'stuck' on long-term dialysis, with its attendant risks and restricted lifestyle.
6. EXPERIENCES OF BIOGRAPHICAL DISRUPTION IN CHILDHOOD AND ADOLESCENCE

6.1. INTRODUCTION

In the next chapters participants' experiences of the uncertainties of ERF, and early disruption to their life course trajectories, are explored. Quantitative analysis and early reading of interview accounts suggested that the chronological age at which participants became ill, whether before or after puberty, had a key bearing on their education and peer relationships, as well as on their family life. Thus, this chapter will compare the experiences of participants who were very young, prepubertal, when they were diagnosed with ERF (early onset), with those who had reached the age of puberty and beyond (late/onset). These will be discussed in terms of 'critical moments', times when an acute health episode made a significant difference to both their education and social relationships, and had important consequences for their developing social lives and identities (Giddens, 1991; Thomson, Bell, Holland et al., 2002). The role played by social resources in the family is also explored.

Puberty, here, is properly assumed to be a process taking place over the period 11-16 years, not a single 'event', such as reaching 16 years, as used for the quantitative analysis. At puberty, the physical body, and therefore the embodiment of RRT, is particularly salient, especially as early childhood CKD/ERF often delays physiological, emotional and social maturation. This meant there would have been a wide variation in the age of puberty across the research participants.

Changes in the physical and physiological body at puberty change peer relationships and impact on emerging adult gendered identities for all adolescents, but interviewees' experiences of being different from other children, originating from being treated differently by adults and peers at school, became greater at this stage. Individual interviewees' experiences of childhood ERF were very varied, and some of the more reflective, if contrasting, insights into the importance of the chronological age of onset came from interviewees who had been ill since early childhood.

When you're growing up, (ERF) affects every part of your life, it's not just physical and sort of nutritional ... (it's) a whole list of things ... be they educational health, spiritual health, moral health, sexual health, social health, you could pick a word and

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8 The terms 'prepubertal' and 'early onset' are used almost interchangeably in the 4 analysis chapters, as are 'postpubertal' and 'late onset', unless either prepubertal (under 11 years) or post pubertal (over 15 years) are clearly preferred.
put health after it and it will be affected by that condition in some way ... financial, it costs money. (Ben, 29 RRT 5)

For the people who get it when they're kids ... it's actually fairly easy to deal with, that's what you are, you've accepted it, you get on with it. The people who get it in mid life, early mid life, it's very difficult, 'cos they're very different, they have to accept it. And I think that acceptance, is very difficult. The people who get it in older life, I think, a lot of them are quite ... rational about it ... you get ill when you're older, and they accept that and ... dialysis is not such a big deal ... sometimes, they actually enjoy it. (Edward, 30 RRT 7)

I've had 27 years' experience of it ... It's down to the individual themselves (to succeed). (Jon, 27 RRT 8)

6.2. EDUCATION

6.2.1. Educational outcomes

Analysis of the survey data suggested that there were differences in the educational achievement of respondents related to the age at which they were first diagnosed with ERF (Appendix 3, Table 14). Subsequent analysis of those who were 23 or older and currently in stable health (N=146) showed that who began RRT before they were 16 years had poorer educational outcomes than those who were 16 and over when they began RRT (Appendix 3, Table 15, Table 16).

The interviewees' survey data (Appendix 3, Table 17) showed little difference in educational achievement between early and late onset interviewees, most interviewees eventually being reasonably successful at school and in further education. However, proportionally fewer of the early onset group said their illness had prevented them from getting the qualifications they wanted (6/22, with ERF at 10 or under, versus 11/18 with ERF over 10), suggesting that they had reduced their expectations of what they might achieve.

These data showed that there were differences in educational achievement, and perceptions of achievement, amongst all study participants, and that these differences were associated with the age at which they became ill. The qualitative data analysis that follows explores the educational experiences of the interviewees.
Table 6.1 Highest educational level attained, interview data

<table>
<thead>
<tr>
<th>Highest educational level reached</th>
<th>Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Below GCSE or GCSEs below Grade C</td>
<td>George, James, Kelly, Kieren, Oliver, Tristram, Wayne</td>
</tr>
<tr>
<td>GCSEs sufficient above GCSE</td>
<td>Daniel, Eugene, Henry, Jude, Luc, Millie, Petra</td>
</tr>
<tr>
<td>Post GCSE vocational</td>
<td>Laura, Lucy</td>
</tr>
<tr>
<td>A level or equivalent</td>
<td>Debra (vocational only), Hanna, Jerry, Luther, Lyn, Mario, Marian, Matt, Raj</td>
</tr>
<tr>
<td>First degree</td>
<td>Ajay, Alice, Amy, Anna, Ben, Carmen, Cecile, Gus, Jon, Sara, Satish, Tanya</td>
</tr>
<tr>
<td>Higher degree</td>
<td>Edward, Marc, Samuel</td>
</tr>
</tbody>
</table>

Note:

1. Debra and Wayne were still working towards, GCSE Grade C in English and Mathematics when interviewed.

2. Henry, Jude and Luc studied to A level (not attained)

6.2.2. Importance of education

Seventy five percent of survey respondents considered education to be very or quite important and there were no differences between the early and late onset groups (Appendix 3 Table 18, Table 19).

Education ... for a child is one of the big things, that's the largest normal part of a child's life ... it's going to school everyday, forming peer groups, that's disrupted a lot if you've got a chronic condition. (Ben, 29 RRT 5)

Parents' data suggested that parents saw their children's education as vitally important. Most talked about how they wanted their children to have a normal life, and this meant going to school just like everyone else. Qualifications were clearly important to parents, but living a 'normal' life and being part of social and peer groups at school appeared equally important. Parents were very keen that their children should be educated with their age/peer group, and several families 'fought' the education authorities to ensure this took place, especially at transfer to secondary school, a critical time for friendship and identifying with peers.

My Mum always made sure that education was first. She never let me ... waste my time playing. So I used to spend my time ... learning, reading books and learning. (Alice, 24 RRT 9)
He had been rejected (initially) for the school (secondary) where all his friends were going. (Then) ... he went into a class with a couple of the same mates, but it was never the same ... and (later) ... the fact that he wasn't at school, he couldn't discuss things with them. (MJames, 16 RRT 12)

I missed the first year of senior school completely ... they said, 'You've got to repeat the year'. My parents went up and were adamant that I wasn't going to repeat the year ... I asked to do the ... end of year exams, and I came in the top 5 in every subject. (Edward, 30 RRT 7)

Pressure to do well at school and complete their education came from parents, who provided the encouragement and support, but not all interviewees attached the same importance to education as their parents, especially some male interviewees.

He was never academic, he wouldn't work, wouldn't study ... we tried everything, in the end we gave up ... he'll (only) do things if he sees need to do it. Now he has been using the computer for his own work, he's no problem whatsoever, but we couldn't get him to go to night school to learn computers. (MJude, 22 RRT 10)

I passed my 11+, no one is sure how ... quite a shock, 'cos I wasn't really that interested in schoolwork ... (At Grammar School) after the transplant, the medication just used to make me tired, and I used to sleep through school. (Eugene, 27 RRT 9)

However, some of the more academically able interviewees clearly attached high importance to educational achievement and the peer respect it offered. Marc, also at Grammar School, expressed his interest in 'exercising his brain'.

Sport's never interested me ... I'm more interested in exercising my brain than my body ... I didn't do it all the time ... I did kind of have carte blanche ... if it looked like a nice day ... I went down the playing field. (Marc, 30 RRT 10)

I enjoyed school mainly because I was good at it ... I commanded respect from the studious students ... and ... from teachers as a result of that. (Samuel, 28 RRT 17)

6.2.3. Critical moments for education

Primary education

Seven of the interviewees began RRT before, or at, foundation level in infant school, and four more before they were 8 (Appendix 3, Table 7). Foundation and primary school were 'critical moments', not only for learning to read, write and understand number work, but also for early socialisation. Few talked about their time off school, but they described its effects.

I think the hardest thing was really getting a proper education ... because my life was so ... much based in hospital. ... it's been difficult to have stable jobs or ... careers ... I was 2 when I had my first (transplant) ... that rejected ... I had a second one at 5 ... I was never really taught even some of the basics in primary ... Math's for example, I've always found difficult. (Satish, 28 RRT 2)
I'd been to 2 previous different schools ... (when) they (parents) relocated me to one nearer where we lived ... The main issue ... was missing school ... not being able to do the work, 'cos I was really tired. (Amy, 24 RRT 7)

The impact of educational disruption at such an early age was compounded for some by further illness, or changes of RRT due to transplant failure, during primary school. Then, the pattern following initial disruption was repeated, with more prolonged periods of time off school, more trips to hospital, more emotional strain and more social costs. Experiences varied enormously, and several interviewees recovered well from repeated early disruption when they later had a period of stable health, whilst others, with poorer health, did not.

I was 5 ... 24 hours to live ... on emergency CAPD ... then got a transplant which lasted for about 18 months, then a second transplant, which lasted for 9 years with a lot of periods of rejection ... I missed a lot of work ... I'd changed to another school before I was diagnosed with the tumour ... (then) I dropped out of school completely ... going back was quite a difficult thing. (Ben, 29 RRT 5)

I think at age (7+), education is ... as much about learning from people, from environments, from getting self-confidence. (Edward, 30 RRT 7)

Secondary education
The next most critical time for prolonged absence from school was the transfer to secondary school. Some began secondary school after a relatively normal childhood, but almost half had never been well. Those who were ill at the actual time of transfer were a mixture of those newly diagnosed (several with CKD from birth), those with failing or failed grafts, and those with serious side effects/co-morbidities.

I missed ... most of my year 6 (primary) education and all my SATS ... I was in hospital the day I was due to start (secondary) school ... I missed probably ... half of year 7, nearly the whole of year 8, 'cos I had my transplant half way through the school year... I (went back) start year 9 ... I missed about a quarter of my schooling in years 9 and 10. (James, 16 RRT 12)

I was ill from birth... (started) dialysis (at 11) ... my first transplant ... went completely pear-shaped ... I was really ill ... that was quite hard. It was just a bad age for stuff to happen ... It was a massive, massive impact ... I was in hospital from the March ... (went back to school) in September. I was quite ill, I didn't have a full week at school for a long time ... I had home schooling and stuff. (Tanya, 28 RRT 11)

I missed most of my first year (at Comprehensive) ... on the educational perspective, it actually got worse. Part way through the year I had to go on haemo, because I'd got a Candida infection around the (PD) exit site and they just couldn't shift it. (Amy, 24, RRT 7)

Anna was well when she began secondary school but became ill at the end of her first year. She was lucky in that the period of educational disruption was relatively short and intense, but her mother's account suggested that Anna had never
recovered the 'lost ground'. Below, contrasting data allow for reflection on the validity of their accounts.

(Anna) lost 1 term ... in hospital and tutoring, then had 2 terms at (day school), so that academic year that she missed out ... she said that that was one of the worst things of her illness ... she felt she'd lost some of her academic ability ... she was always striving to try and get back to where she had been. I think that actually took quite a toll. (MAnna, 28 RRT12)

I couldn't go back to school immediately ... because of various hospital appointments and stuff ... I did home-tutoring for 1 term, then went back to boarding school after that. It's just gone from there, the hospital appointments got less frequent, I carried on as normal really. (Anna, 28 RRT12)

Mainstream secondary schooling offered structural barriers (year groups, timetabling) to attainment for interviewees who could not attend regularly. For some interviewees, hospital schooling helped to reduce the educational impact of prolonged in-patient stays, but this also separated them from their peers. Hospital schools helped most at primary level, but offered no subject specialist teaching for secondary education. However, it was possible that more middle class families/children did not value what the hospital schools could offer and did not use them.

I think it was about 6-8 weeks off whilst I had the transplant ... school sent me all the work and the hospital teachers helped me ... I didn't lag behind at all. (Jude, 22, RRT 10)

When you're (in hospital) for 10 months, you learn adult skills, learn about other things ... I used to read a lot ... your mathematical skills, your language ... your science ... (are) obviously developing ... Hospital school ... I avoided like the plague ... My parents probably educated me in a ... non-educational sense. (Edward 30, RRT 7)

However, interviewees who were ill before or at secondary transfer had entered secondary school with a growing sense of being different from other children. While secondary transfer was successful for some who were already ill, others found it hard to adjust.

I left (secondary) school, not only because I had (health) problems, but I wasn't happy at school ... then I had home tuition. I went to 2 or 3 different schools, where there were other children, young girls mainly... (pregnant). I learned a lot from places like that, 'cos it was a lot more comfortable ... I didn't feel different there ... so it suited me really well. (Wayne, 20, RRT 15)

Post 16 education and training
Leaving school and starting work or college was another critical time for being ill again or for beginning RRT. Some of the prepubertal group were ill again just as they left school and started college. This experience paralleled that of starting primary
school, and later educational difficulties compounded any earlier difficulties. Oliver (home educated), was denied the college place he had been offered at 16 because he was losing his first transplant, and lost what proved to be his 'last chance' of 'normal' life. Kelly with severe headaches, lost her college place, when staff thought she was 'not serious' about work.

I did (try for college at 15) but ... the first kidney was starting to fail, and they (sic) thought it probably be better if I remained in home education ... because it would be difficult ... keeping track of medication, and hospital appointments ... fitting it all in around course work and exams. (Oliver, 26, RRT 7)

I was at college (17 years) but ... 'cos of the hospital and headaches (IH) I was having too much time off, so they had to say they didn't want me no more. (Kelly, 17 RRT 4)

Some of these prepubertal onset interviewees recovered educationally from a prolonged poor start, like Edward, but others struggled to get basic qualifications.

Most interviewees who began RRT at 16 or over (N=11) had experienced a relatively healthy childhood up to 16 and had participated fully in life at school, including some, but not all, of those who knew that their CKD would eventually progress to ERF. Some of this group were still studying when they first started RRT, some had just finished, and were looking for work. Their entry into college (or employment) was delayed by ERF, but experiences again varied. Samuel (acute ERF at 17) spent an unplanned year in retail after initial transplantation, reconsidered his university course, and chose a different university. George (long-term CKD) went into ERF at the beginning of a vocational training course for under qualified school leavers, and never felt well enough to continue.

I had the dialysis problem at the wrong time ... (at) horticultural college ... I'd just started and these problems occurred, then I thought I got them all sorted, and I started (again) and they all re-occurred again ... so I had to stop the course. (George, 29, RRT 18)

Included in this group were three who had ERF at 18. Gus and Henry, who postponed/refused timely treatment, suffered serious post-16 educational disruption, and Laura who was ill just as she finished vocational training, and had to change completely her career plans.

I'd been (at university) for about a couple of months ... I went back ... finished my first year, got through. My second year, it all went really wrong and I got really swollen, really quickly and I had to drop out. (Gus, 25 RRT 22)
I had a terrible cramp and sickness ... and going from sort of no medical intervention to 100% ... I couldn’t work, couldn’t go to school. I actually stopped my education and I was just ill all the time, completely. (Henry, 30 RRT 19)

The overall picture was of a group of young people whose education was being continually interrupted by ERF, but for whom missing school at ‘critical’ times, such as a starting a new ‘phase’ of education, was especially disruptive, and for the early onset group, accumulative.

**Examination times**

Most interviewees who were ill immediately before or during ‘external’ examinations found their performance affected the rest of their lives. GCSE examinations are an acknowledged educational milestone, and so called ‘good passes’ at GCSE, the accepted ‘passport’ to further education and employment. Interviewees’ GCSE results offered them a reference point in terms of educational attainment, comparison with peers, and an opportunity to reflect on whether their illness had made a difference to their educational achievement.

For some, poor GCSE results changed their lives. Those who could, continued studying GCSEs in basic subjects at post-16 college, or if they had 3 or 4 GCSEs at grade C, stayed at school.

‘Cos I’d started haemo... my GCSE results were really quite bad ... Cs, Ds, Es and an F. I was really, really upset ... I thought, ‘What am I going to do?’. (Amy, 24 RRT 7)

It’s very tough ... I got one GCSE ... I only (did) my art GCSE, all the rest, I hadn’t had enough revision for ... I’m currently studying English and Math’s, trying to get my GCSEs. (Wayne, 20 RRT 15)

I did apply for GNVQ ... (The school) accepted me ... then ... gave me a heave ho, 2 hours later ... minimum entry level was 2 Ds, and I had one D ... (then) all the colleges had no places ... I was going to have to go out and get a job ... Connexions... found a local course for 22 weeks. (James, 16 RRT 12)

I was really upset ... teachers didn’t expect me to finish my GCSEs ... I wasn’t expected to hand in any coursework. I was under the impression that my exams would be double marked for my coursework, it didn’t happen and I didn’t get very good results. (Raj, 22 RRT 16)

Several who did well at GCSE reported their illness had made doing their GCSEs more difficult for them, and some thought they would have done better at GCSE if they had not been ill.
Throughout school they were OK with me missing time ... They'd give me the work to catch up, but with my exams, my form tutor ... didn't tell me when my exams were starting. (Mario, 28 RRT 15)

I kept missing the lesson ... I tried to sort of catch up, but ... they'd never told me about this coursework was due (laughs), I remember, really rushing to get that done, really rushing. (Lucy, 27 RRT 9)

For those who were more successful at GCSE, A level examination time was equally critical for those who had plans to go to university or into a good job. Lyn gave up her A level course; Ajay did badly and struggled to find a professional course that would accept him, then struggled to qualify. Luc began work with good predicted A level grades, started work, but found he had failed. This juxtaposition of events had devastating consequences; he became depressed and withdrew from the 'social world' for three years.

My (transplant) failed when I was taking my GCSEs ... when I started my A levels the next year, I found it quite difficult to keep up ... I missed the first day and the first couple of months ... I never finished because I missed too much. (Lyn, 19 RRT 9)

They told me ... in March ... that I'd never really get any better ... My A levels ... I did them, but I failed them all ... even by a few marks ... it's a sort of regret. (Luc, 24 RRT 18)

In summary, two typologies of 'critical moments' were identified in the education of the interviewees: educational phase changes and 'external' examination periods. The early onset interviewees experienced major disruption at more of these 'moments' than the later onset group, although several late onset interviewees also experienced serious disruption to their examinations. Overall, the data possibly begin to explain how, by missing school at more of the 'critical times', the early onset group became more likely to underachieve, or achieve educational goals later, than those who became ill later.

**6.2.4. Perceived impact of disruption to education**

Survey data from the interviewees (Appendix 3, Table 17) showed that 17 felt that ERF had prevented them getting the qualifications they wanted, and 26 felt it had upset their future plans. However, the interview data pointed to limitations in interpreting the survey data, as it revealed that many of the interviewees who had claimed that they reached GCSE level, had in fact very few GCSEs at grade C or higher, if any.

Amy, like several other interviewees, experienced so much disruption in one early year at school that she returned to school in the year group below her own. Others
planned, or took an unplanned, gap year between education and higher education/work. Some planned to have a transplant in that year, some, including Samuel, felt they needed to adjust to beginning RRT, and others could not find work.

*I left it a year... when everyone of my school year (was) going to Uni, I wanted to go and have the transplant (Mother donor). (Carmen, 24 RRT15)*

*I'm just having my gap year, and I'm on the waiting list now ... just waiting for a kidney. (Hanna, 18 RRT 17, family donation not possible)*

*I took a year out to try and find work. (Cecile, 26 RRT 8)*

These kinds of delays meant that affected interviewees did not reach educational milestones at the same age/time as their peers, some seeing themselves as 'falling behind'.

**Early onset**

Many of the educationally successful early onset interviewees, had experienced a long period of stability at school after successful transplantation, and (after the first year) had few interruptions beyond regular clinic visits. Others had fared much less well. Only limited indications of what interviewees thought they might have achieved had they not been ill could be derived from the data. Some compared themselves with siblings, like Oliver, whose sister was also taught at home, but had gone on to university.

*I missed a lot of school having it very young... I let myself down... I still feel that I didn't achieve enough ... I left school without GCSEs. (Debra, 27 RRT 4)*

*I've always considered myself a lot slower than my sister. She's incredibly intelligent ... after she was taught at home, she went to a nearby college, from there she went on to University ... and got a degree. (Oliver, 26 RRT 7)*

Obviously many factors affected educational achievement, including gender, as well as their own attitudes and attributes including cognitive ability and/or socioeconomic factors. Some male interviewees suggested that their own attitude to school had contributed to their underperformance, whereas females tended to emphasise how hard they had worked to catch up.

*I squandered my education ... along with a lot of my friends, you don't appreciate what you've got until you lose it ... I never found education particular difficult. (Henry, 30 RRT 19)*

*I had 3 months off school, best thing in the world I thought at the time. (Jerry, 25 RRT 12)*
I had home schooling ... I was quite swatty, and I was always quite intelligent .. I didn't miss out. (Tanya, 28 RRT 11)

Family support made a difference, as exemplified by Marc, whose parents separated. He left school at 16 with good GCSEs, and 'drifted' for many years, perhaps because the kind of encouragement to continue studying he might have expected from his professional father was missing.

I flitted from job to job really ... just basic admin work around the city, just picking up office jobs. (Marc, 30 RRT 10)

Educational outcomes poorer than expected in relation to chronological age, also separated the interviewees from their peers, and were likely to impact negatively on interviewees' developing sense of self. It was clear from the data that there was a dichotomy in how examination underachievement was perceived: some felt they were successful in spite of adverse circumstances, others perceived themselves as 'failures'. Comparing Henry's evidence above with that of his mother, the effect of 'failure' on his self confidence was perhaps more serious than he revealed in his light-hearted attempt to pass it off, by showing it was shared with his friends.

His education was interrupted ... from day one, his health interrupted it. He's very bright, and recovered from that ... but he'd lost his confidence ... (GCSEs?) he was really ill by then, he did outstandingly well in (the few) he did, but ... internalised that as failure. (M Henry, 30 RRT 19)

Postpubertal onset
For those who began RRT after puberty, it was equally difficult to get any objective measure of what they might have achieved educationally had they not been ill. But for most, the foundation stages of their education and early learning did not appear to have been disrupted by CKD or associated comorbidities; exceptions were Henry and Wayne, who had both been seriously ill from birth.

I could have done better ... While I was trying to revise, I was falling asleep and stuff ... I got 11 and a half (GCSEs), but ... some were Bs, a couple of marks off As, and so on. (Marian, 19 RRT 16)

I had a few problems with examinations and stuff (at Uni) ... and I decided to change course ... I see it now as a blessing, 'cos now I'm doing something that I actually want to do. (Raj, 22 RRT 16)

I was looking for optometry ... (X) was a very sort of last resort ... I would have gone into possibly banking ... but I didn't get the grades. I didn't get the grades for (X) either, I had to take an entrance exam ... fortunately I got in. (Ajay, 28 RRT 17)

For the whole of my finals year I was on dialysis. And it was quite a struggle, I would have got a 1st but I got a 2(i). OK, so I didn't get the degree that I wanted, or would
have expected, if I hadn't had the turbulence or the trauma of dialysis in my final year. (Samuel, 28 RRT 17)

For other interviewees who began RRT at this stage contrasting experiences and outcomes were possibly more attributable to innate ability and social factors than illness related per se.

6.2.5. Conclusions for education

The survey data demonstrated that educational outcomes for survey respondents were associated with the age at which they became ill (Appendix 3, Table 14, Table 15) and the interviewees' survey data showed that almost half felt that their illness had made a difference to their achievement (Appendix 3, Table 17). However few were willing to blame their illness in their interview accounts. In this respect, their own survey data present a more negative picture than the interview data, and suggest that the need to present themselves positively at interview made many interviewees hide their feelings about their attainment levels.

The interview data suggest that for many of those who were ill early in childhood, the effect of educational disruption on their educational progress was accumulative, from failure to acquire basic knowledge and skills at primary school, through absence from school at the beginning of new educational phases and critical examination periods. Some of the more able interviewees who were ill early in their childhood had experienced major disruption and set backs, even at critical stages, and had been able to overcome some effects of educational disruption, and get degree/s. Several, while progressing with further education, were simultaneously struggling (or had struggled) to get GCSE English and/or maths. Others, more than survey data might indicate, had no GCSEs at Grade C or above.

Most of those who were relatively healthy up to puberty had experienced a sound primary education, and had fairly clear indications of their educational potential before they became ill. The educational impact of beginning RRT during puberty or later depended mainly on whether they missed key examination periods, and how far they had been able to mitigate its effects.

Overall, the instability and unpredictability associated with the different modalities of RRT, and the chronological age at which the interviewees first began RRT, appeared to have a crucial bearing on whether they reached their academic potential at all, whether they gained the necessary qualifications to take them into employment, and,
importantly, whether these qualifications were gained at the same time as their peer group. For all, individual attitudes, attributes and abilities played an important part.

Whilst there are no 'controls' per se, by comparing the educational experiences of prepubertal and postpubertal onset groups, the qualitative evidence suggests that the age of onset, the timing of disruption, and the cumulative effect of long and frequent disruptive spells, help to explain the higher levels of underachievement or delayed achievement experienced in the prepubertal group. Moreover, these findings are consistent with, and in part explain, the statistically significant findings from the survey subset data, that those who are under 16 when they begin RRT have poorer educational attainment, than those who are 16 and over (Appendix 3, Table 15, Table 16).

6.3. PEER RELATIONSHIPS AND ADOLESCENT IDENTITIES

Peer relationships at school are an essential part of children’s wider social development, and making friends, joining in and being accepted by their peers all contribute to developing self confidence and a positive social identity. The school curriculum provides formal teaching in personal and social education, but it is the informal curriculum which provides the social space for children to make friends and share interests and activities. Evidence presented in this chapter will explore how, and how far, participants' social relationships and emerging adult identities were affected by childhood ERF.

"It's made some difference ... especially as a kid, I was different, I had to be a bit more careful ... but it didn't really affect me in any way apart from the time off school, I still saw my friends when I got back home. (Jerry, 25, RRT 12)"

6.3.1. Critical moments for making friends

Changing school
Parents of the prepubertal onset group recognised that starting at the same secondary school at the same time as their friends was important, and at least three parents had overturned decisions by statutory authorities to separate their children from their peers at this stage. Data from interviewees' mothers allow a fuller picture of challenges to peer relationship to emerge, than data from interviewees alone.

"James lost his friends ... we both (parents) worry deeply about that, because he'd been very sporty, very outgoing ... We'd fought to get him into the same school as his friends. (MJames, 16 RRT 12)"
I don’t think she had many friends at (school Y) ... she joined a year that was already established ... I think it was very difficult for her. (MAnna, 28 RRT 12)

Even if interviewees’ were older, it was not easy if they were ill at a ‘critical moment’ (here starting college at 16).

I missed the first day and the first couple of months ... the girls (were) just in their little groups and I got pushed right out. (Lyn, 19 RRT 9)

Some of those who were first ill after puberty also experienced disruption at times that were critical for friendships. For example, Raj was angry because the school staff refused to let him join a residential school trip in the summer, just before he joined the sixth form.

They wouldn’t let me go (on the trip)... because I had dialysis ... they were scared ... I was pretty upset ... all my fellow students were out getting to know each other ... I was stuck at home. (Raj, 22 RRT 16)

For some, perhaps with greater maturity and/or better health, a new ‘start’ offered new friendship opportunities, and a chance to leave childhood experiences behind. Several interviewees, who had felt different from other children at school, enjoyed a ‘normal’ life at college/university, although not all disclosed their health/transplant status.

My most enjoyable academic time was at University because you really can be yourself there ... in a way you can’t anywhere else. I had a great group of friends, and (RRT) was never an issue. ... I was conscious of it all the way through school, so (at) University I thought, ‘I’m just not going to let it be an issue for me any more’. (Sara, 27 RRT 2)

**Puberty**

For those with ERF-related delayed physical and sexual development at puberty, puberty was especially problematic. Transfer to secondary school coincided with the onset of puberty, and, as their peers reached puberty and their growth accelerated, several early onset interviewees remained small and sexually immature9.

At 14, it was ... a big issue ... they wanted to get me up to about 5 foot. I had counselling to decide whether to go for (growth hormone) ... we didn’t go for it ... there’s times where I think, ‘Oh if only I was a bit taller’, other times I think, ‘I’m all right, I’m not bothered about being the same size as everybody else’. (Amy, 24 RRT 7, 145cm)

(At) middle school, secondary school, it all started to go wrong... I was more isolated ... I got treated differently by the teachers, I got treated differently by friends ... When

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9 Fourteen of the eighteen interviewees with RRT under 12 were less than 168 cm tall, compared with 6/16 RRT aged 12 or older (not all provided height data).
you're fighting to be the same as everyone else, get involved with everyone else ... I got picked on 'cos of my size, because I was smaller than everyone else. (Kieren, 29 RRT 7)

End of formal education
Leaving school/formal education was a critical time for interviewees who were not ready to move into adulthood with their peer group. For those who lived in small villages especially, opportunities for social interaction became more limited after the end of formal schooling because school friends had often moved away. Several (4) were affected by this, but Luther and Oliver were 'extreme cases' who became increasingly isolated as they got older.

I had loads of friends when I was at school ... I seem to have drifted apart from them ... There's a couple who sort of 'pop by' ... I've got one friend in particular who's always away with work ... he's stood by me ... we used to play pool ... I used to be captain of the team ... I've even got rid of my pool cue now. (Luther, 27 RRT 6)

When I was a teenager ... there's no kind of people of the same age, so you can't build any friendships, it was all very difficult. There's a pub down the road but that's about it. (Oliver, 26 RRT 7)

Thus, critical moments for peer relationships, mirrored those for educational attainment, and prolonged or sudden absence from school affected peer relationships, especially at year or educational phase change. Crucially for peer relationships, growth and maturation became important, particularly at phase change. Overall, social participation appeared likely to decrease as they got older.

6.3.2. Embodiment and peer relationships
Throughout childhood, the physical body becomes increasingly salient for peer relationships, and development of a positive adult identity. Anatomical and physiological abnormalities associated with ERF, meant many study participants looked different from their peers from an early age, and their dependence on obtrusive RRT technologies, far and beyond simple medication, especially those associated with dialysis, added to their deviation from 'normal'.

Visible changes in appearance after transplantation
The most highly visible and sudden embodied changes to the interviewees' appearance occurred immediately post transplantation\(^{10}\). Few of the very early onset group described these themselves, but their mothers talked about them. It was the later onset interviewees, like Ajay who talked about the immediate impact on his

\(^{10}\) Only Hanna and Gus had never had a transplant.
appearance, and how difficult it was to go back to school, see their friends and meet people.

The first year... was very, very hard in terms of ... the way your looks change ... at that age when obviously your looks are most thing to you ... I'd just gone into the 6th form ... some of my friends ... walked straight past me 'cos they didn't recognise me. I had really, really bad acne from the prednisolone and I'd put on a lot of weight. (Ajay, 28, RRT 17)

Looking in the mirror and thinking, 'I didn't used to look like this'... when everyone else was... fairly competitive, everyone's wearing these clothes and doing their hair, especially when you're starting to meet boys. (Anna, 28 RRT 12)

From being very pretty, slight ... she turned into a hairy ... tubby round-faced, little girl. We did something about the hair ... She hated the hair, absolutely hated it. (MAnna, 28 RRT 12)

We were so concerned ... he wasn't talking about anything, he wasn't happy with his appearance because he was so bulked up on steroids ... there was an awful picture of him, a sad picture, near the end of the school year ... he had been so ill throughout the year, I actually get upset to talk about. (MJames, 16 RRT 12)

Experiencing such a noticeable change in appearance, almost overnight following transplantation, is obviously different from the experience of living with many other chronic diseases where change and/or deterioration is more gradual. It is clearly not unique, and is shared by others who have steroid treatment, but is obviously challenging during periods in the life course when appearance is particularly important.

'Hidden from view' body scars
Some interviewees described the impact of the disfigurement of their bodies in childhood, and how they hid scars from their peers. They all had multiple scars on their body resulting from several (or many) operations; their dialysis scars were small and numerous, but in places where they might easily be seen; their transplantation scars (abdominal) were much bigger, but usually hidden from view.

I wouldn't wear bikinis ... short tops, because I didn't want people to see my tubes ... At school, I wore a dress to try and hide it ... when I got my transplant (aged 19) I was a bit ... nervous ... I got help ... (from) counsellors within the renal team ... we gradually got into a situation where I was able to wear a bikini. (Amy, 24 RRT 7)

I did feel different during primary school, mainly because of the scar. (Sara, 27 RRT 2)

I never did PE ... I was ill, then when I was on dialysis, there was this tube coming out my stomach, so I never wanted to get changed. (Tanya, 28 RRT 11)
This (dialysis) scar ... at first I was very self-conscious ... I hid it with my hair ... then I thought, 'OK fine', I'm all right with it now. (Hanna, 18 RRT 17)

Visible and invisible sexual immaturity
Embodiment of ERF at puberty was experienced in a gender specific way. Few talked about their sexual immaturity directly, but spoke instead about its implications. Two talked with difficulty about the absence of the normal signs of sexual maturity, Amy said counselling had helped her.

Because of (diagnosed disease) ... they don't go through the adolescent bit ... when they've got renal failure and stuff. He never went through that. (MLuther, 27 RRT 6)

Secondary school ... was probably the worst time ... I wasn't happy ... everybody was just growing up really fast, and I wasn't. (Wayne, 20 RRT 15)

I was small in every department ... physically my breasts ... (aren't) anything great. (Amy, 24 RRT 7)

I've got undescended testes, so ... nothing was happening ... They put me on testosterone replacement ... it's only in the past year that things have started to change. (Jude, 22 RRT 10)

6.3.3. Stigma and spoiled identity in childhood
The identity 'kidney patient', given to early onset interviewees by NHS staff, influenced how they saw themselves from a very early age. They were also similarly labelled by staff at school, where NHS reports/ interventions ensured they were treated differently by their teachers. Actions taken were always 'in the child's best interests', as perceived by responsible adults, but accentuated the differences between interviewees and their peers, and meant limits to participation and underachievement were expected and excused, in a sense, negative discrimination.

I'd always go home at lunchtime ... I had a urine bag on my back that always had to be changed ... I was just different to everyone else. (Kieren, 29 RRT 7)

Nurses came out to my school, and said what needed to be done if anything happened ... the other kids were told that they had to ... be careful because (of) having tubes round my stomach. (Amy, 24 RRT 7).

Some interviewees continued to be treated differently by staff as they progressed into secondary and tertiary education, as previous evidence from Raj and Oliver indicated.

I used to roam in late ... very little (was) said ... I thought it was the same for everybody, until about 12 months ago, one of my friends said, 'You must be joking, we'd have been castrated probably if we'd have done it'. (Marc, 30 RRT 10)
I did the NNEB, and they originally put me down for (a lower qualification) ... 'cos they didn’t know if I could cope with how much work was involved in an NNEB. (Lucy, 27 RRT 9)

Some of those who were ill before puberty were bullied or teased at primary and/or secondary school, often because they were small, or sometimes just because they were/looked ‘different’. New unwelcome labels were given to them by their peers, such as ‘titch’ and ‘shortie’. Both the male and female interviewees were stigmatised in this way, but female interviewees referred more to teasing, while male interviewees talked about being bullied. Their mothers’ data give more emotional weight to the kind of experiences some interviewees described less emotively.

It’s a bit daunting looking up to your friends and they’re calling you all these names, like titch and shortie ... They used to call me midget, and man mole. (Luther, 27 RRT 6)

(As) a child I always had ... people bullying me ... I had to have something, to put myself ahead ... to show that, ‘OK I’m not healthy, and ... I don’t have other things that other girls have, but I am clever’. (Alice, 24 RRT 9)

I was teased ... about my weight and being so small ... It was just about looking different really. (Sara, 27 RRT 2)

Satish revealed how much he was teased at primary school by contrasting his primary and secondary experience.

I wasn’t really teased, ‘cos I think everyone who was in my class, knew ... so they knew how to approach me, so it wasn’t too bad ... secondary school, was a lot better obviously (Satish, 28 RRT 2).

Interviewees who had ERF, or early CKD, but had grown normally appeared not to have been bullied at all, and talked only about their subjective feelings of being different. Thus, they appeared to have experienced adolescence without having been stigmatised by others on account of their illness.

6.3.4. Social participation, gender and identity

Participation in everyday social activities supports feeling ‘normal’, and success in such activities, within and outside, education contributes to developing eventually a positive adult identity. However, for the interviewees, full participation in the informal school curriculum meant participating in individual and team games and sports, going on school trips, and engaging in dance, drama and music; activities which were likely to present difficulties for children with ERF.
Early childhood
For the most part, any difficulties interviewees experienced, were presented factually, perhaps understated (Satish below), but again, their mothers' data gave more emotional weight to the kind of experiences interviewees described. For example, Jude's claim to normality was contested by his mother's evidence.

In between all of that (illness) you miss doing things you see other people doing ... social life gets a little bit affected. (Satish, 28 RRT 2)

If I hadn't joined in with what other people were doing, perhaps I would have been a bit more of an outcast than I was... (At secondary school) I wasn't so much teased as... pushed out and excluded. (Wayne, 20 RRT 15)

I was ... a normal child, a normal ... young teenager. (Jude, 22 RRT 10)

He'd always gone for younger friends (because) he was very immature as well ... We had colossal behaviour problems with him at one stage, we couldn't get him to catheterise or anything ... and, he'd been bullied at school. (MJude, 22 RRT 10)

The age of onset made a difference here, as those who were ill early in childhood, experienced the greatest difficulties in 'joining in'. For Henry, everyday social life became more important than educational achievement because he was ill 'all the time'.

I did (A levels) at college, but ... I was beginning to have quite a lot of time off, and I was into ... being sociable ... all that kind of thing, and, 'cos I knew it wouldn't last, I wanted to spend as much time with my friends as possible. (Henry, 30 RRT 19)

Participation in sport
All the transplanted interviewees were told to wear a kidney guard when they played contact sports, and several mentioned that it was uncomfortable, constraining, and a constant reminder of being different from their peers.

I feel aware of (the guard) when I'm playing ... If I don't wear it, (I) feel normal, if I do wear it, I always remember I've got that (kidney). (James, 16 RRT 12)

There were clear gender differences in how, and how much, the early onset interviewees talked about particular peer activities. The young men talked much more about sport at school than the young women, and football was clearly important for male interviewees in establishing and sustaining their identities as males. However, most were small for their age and found that success in sport eluded them.

I still played football... they treated me OK at school ... so I don't really think it had an effect on me ... I just got on like a normal 8, 9 and 10 year old. (Jon, 27 RRT 8)
I was part of the basketball team at school ... I did all PE and all the different sports. (Jude, 22 RRT 10)

Even with the transplant ... when they pick their own teams, you're always the last one. I'd always wanted to play football, I'd always wanted to get involved in like school team games, and I never got involved. (Kieren, 29 RRT 7)

However, success in sport at secondary school earned peer respect for both Edward and Samuel, and contributed to an enduring positive sense of self for both.

It was quite a rough school, I loved it ... I played hockey, several hockey teams ... county tennis, 'cos if you're sporty, you get in with the right gang at school, that makes quite a big difference. (Edward, 30 RRT 7)

I went to quite a tough state school ... I commanded respect from ... those who were less ... into their academic sides ... because one, I was good at sports, and secondly, I could take care of myself. (Samuel, 28 RRT 17)

Fewer young women talked about sport in terms of their social identity. Those who did, provided contrasting experiences, depending on their age of onset. Both Sara and Tanya had been ill from birth, and both had enjoyed a long period of stable health but had been discouraged from sport or not enjoyed it; for Marion and Carmen sport had played an important role in positive identity development, during their more 'normal' childhoods.

(At) primary school ... they wouldn't let me play contact sports. I was never very sporty, but I would have liked a chance. (Sara, 27 RRT 2)

I always got out of PE ... (after the transplant) some was all right like tennis and trampolining, but running and everything, I used to hate, hockey I used to hate, netball I used to hate. (Tanya, 28 RRT 11)

I used to be one of sportiest people I knew ... I was basically doing a sport nearly every single night. (Marion, 19 RRT 16)

I was in the netball team, the football team, I played rounders ... I played all the sport. (Carmen, 24 RRT 15)

**Participation in 'adolescent' activities**

In adolescence, normal peer interactions outside educational settings presented different challenges. For example, age appropriate clothes became harder to find, especially for smaller female interviewees, whose peers became increasingly taller and increasingly adult in body shape.

I have got big kidneys, so my tummy bulges out ... if the waist fits, it's too long and too baggy in the legs. If the legs fit, it's too narrow ... I hate shopping for clothes. (Hanna, 18, RRT 17)
RRT imposed time constraints which limited social availability, and for those on dialysis, the inflexibility of hospital/satellite HD schedules made spontaneity almost impossible.

When I want a night off (HD) 'cos I'm going to a friends party ... I have to ask at least 2 or 3 weeks in advance ... being teenagers, my friends don't make up their mind until a week or two days in advance, so it's quite hard, when they say, 'Oh can you come on Friday?' (Hanna, 18 RRT 17)

Social drinking in pubs and clubs was difficult for those who looked immature and/or small for their age, and some found it too stigmatising to be refused entry to a bar, repeatedly, and gave up going to the 'pub'.

Looking like a 12-year-old trying to get into a club that's only for 16s ... that was never going to work. (Mario, 28 RRT 15)

Social drinking, even a cup of coffee/tea was difficult for those on dialysis because of fluid restrictions (often 500ml/day). Drinking alcohol to excess was potentially dangerous for all; it is a recognised cause of sudden death in dialysis patients because of fluid overload on the heart, and in transplantation, it damages the graft. It was possible that Jerry's drinking behaviour had accelerated the loss of his already failing transplant.

It feels horrible to go to a bar and not have a drink in your hand ... so I tended to be quite solitary at Uni. (Ben, 29 RRT 5)

I rarely went out on a night out or ... try and go to the pub. All of my friends did ... I never did any of that. I think lost out. (Jon, 27 RRT 8)

I still had drinks ... the first kidney just ... wore out ... they didn't say it (drink) was a factor... a couple of times ... I'd had far too much to drink, I did end up in hospital ... it was around that time that (the results) were starting to go down and down, (Jerry, 25 RRT 12)

There was possibly a gender effect here, as it was the male interviewees who talked about drinking alcohol in these kinds of terms, whereas only two (late onset) females mentioned drinking alcohol socially. These data suggest that participating in gendered social activities could be more of a problem for the male interviewees.

Casual sexual relationships are another part of 'normal' adolescent life, but few early onset interviewees spoke about adolescent intimate relationships at all, except those who had been repeatedly rejected, or had found a partner. In contrast, some of the postpubertal group (below) talked about their sexual lives in 'normal for age'
language, at least until they became ill, but most had only continued if successfully transplanted.

The teenage years were probably the most traumatic for him, really. I mean he did have a girl friend once, but she quietly disappeared, that sort of thing. (MGeorge, 29 RRT 18)

I had plenty of boy friends, but none serious or anything like that ... they all came to see me in hospital, one of them disappeared for an hour and we found him playing on the rocking horse outside the front of the hospital. (Carmen, 24 RRT 15)

I've known him ... for about 7 years ... we hadn't seen each other for 2 years, 'cos he'd gone off to college ... then we met up again and ... just sparked. (Marian, 19 RRT 16)

I think actually I met my first girl friend in hospital. (Samuel, 28 RRT 17).

Overall, social participation with peers became more difficult in adolescence when engaging in some 'normal for age' peer activities presented difficulties.

6.3.5. Summary peer relationships and adolescent identity

Prepubertal onset
Development of positive adolescent identities through age-appropriate social interaction with peers was problematic for many who began RRT before puberty, especially those who were small for their age. Again, 'critical moments' in their lives, like missing the start of school, made making and retaining friends more difficult for them, than for the later onset group. The early onset group were increasingly discredited and stigmatised by their peers, especially by their 'abnormal' appearance as they grew older. They also experienced being treated differently from other children by professional adults. Embodiment of RRT technologies led to difficulties associated with participating in social activities, especially sport, either because they were small, needed to wear a protective belt, or because they were at higher risk of injury; and were felt more keenly by the male interviewees. The data also suggested that boys had more problems with bullying and teasing than girls.

Performance of age-related identity became more difficult during and after puberty when delayed physical and sexual maturity increased the differences between many of them and their peers. Several talked about the effects of the delays in (or absence of) sexual maturation on their relationships, but most simply did not talk about it.

Postpubertal onset
Interviewees who were ill after puberty were less likely to be developmentally delayed, in both a physiological and a psychological sense. They talked less about
being stigmatised, but were more likely to talk about what they had lost, what they could no longer do now they were chronically ill, and how their appearance had changed. They also made more references to heterosexual relationships as part of normal everyday life. When they were 'discredited' by changes in their appearance after transplantation, several did not go out socially until their appearance had reached some semblance to previous 'normality'. They were not bullied or teased in the same way as the prepubertal group, perhaps because their peers were more mature.

Overall, for all the interviewees, development of a positive identity in adolescence, through social interaction with peers in environments such as sport, pubs, clubs and parties, was constrained by time availability, the restrictions imposed by RRT, especially dialysis (diet, fluids), the visibly immature body, and/or the contraindications for drinking alcohol. After leaving school/education, social interaction was more difficult for those who lived in isolated communities.

6.4. SOCIAL RESOURCES IN CHILDHOOD AND ADOLESCENCE

The focus in this section is on the role social capital played in the everyday lives of families of the interviewees, especially those of the prepubertal RRT group. Social capital in the families of the later onset group was also important, but used differently, as the children were older and more independent. Different kinds of social capital helped to mitigate the impact of ERF on all interviewees, their siblings (if any) and their parents, at different stages in the disease trajectory.

Social class was difficult to ascertain, but survey data showed that 24% of respondents lived in rented accommodation with their families (Appendix 3, Table 21), and subset analysis showed that significantly more of the early onset group (35%) were living in rented accommodation with their families, than the later onset group (13%) (Appendix 3, Table 22).

6.4.1. Family social capital

The social 'costs' of having a child with ERF were carried initially, and for many years, by the whole family. Very few prepubertal interviewees talked, like Ben, about the impact of their illness on their families, most appeared to take for granted the support they had had, from accompanying them to hospital, to providing a donor kidney. The parents' data provided evidence of the early impact on the family, and
the initial and continuing anxiety and uncertainty that made normal family life very difficult.

When you’re a kid it doesn’t impinge upon you in the same way as it does when you’re older, ‘cos your parents are there to look after, and if anything it affects the parents more than the child. (Ben, 29 RRT 5)

Most of the children we met had been long-term ill ... The destruction on theirs and their parents’ lives was total ... hugely desperate parents and children, who had been living under this for year after year after year. (MAanna, 28 RRT 12)

Gendered social roles meant that much of the care was undertaken by mothers, but fathers were not unaffected.

(My husband was) weighted down with more worries than me, although I was worried, I could get on and do things ... he just couldn’t function properly .... I wonder what our lives would have been like ... It’s had a profound effect ... we just didn’t function maybe as we should have done. (MTanya, 28 RRT 11)

All the prepubertal onset interviewees, as far as could be ascertained, lived with both parents when they were first ill, and the presence of both parents to support each other at this stage was a valuable resource. Most prepubertal onset interviewees were admitted to local hospitals as emergency cases, then transferred to specialist paediatric units. Whilst some were fortunate and lived near a paediatric unit, most lived very far away, then one parent had stayed in hospital with them. Both interviewees and parents talked about how family responsibilities were shared: mothers being hospital-based during the week and fathers at the weekend, relatives taking care of siblings.

Most interviewees were put on PD initially and ‘sent home’ when stable, which helped the whole family to reclaim ‘normal’ family life. However, interviewees’ parents/mothers, had to become ‘nurses’ and keep them safe from peritonitis, as infection was usually attributed by staff to ‘human failure’.

I got peritonitis about 3 or 4 times, I was in and out of hospital ... which was quite hard on my Mum and Dad ... They put me on the machine over night ... they’d had the training, but I was still getting infections, so they must have felt pretty, really guilty. (Tanya, 28 RRT 11)

I hadn’t been home at all ... I slept in the hospital, in the ward and things, and rang back and let (my wife) know what was going on ... that lasted ... a few weeks ... Meantime they were putting ... me through a (CPD) training programme, then my ex-wife came down when she had time, and we did the whole thing ... I had to teach my wife how to do it, all the exchanges, the whole programme. (DDaniel, 27 RRT 10)
Transplantation made different demands on the family resources because of the long period of hospitalisation involved, again making 'normal' life almost impossible. It also created new anxieties and uncertainties about whether it would be successful or not.

You can't plan ... even after his transplant (at 12), you think it's Utopia, I was ... every day at the hospital, and never knowing whether I'd be allowed home again that night or not. For 3 months, I was there every day. (MJude, 22 RRT 10)

She had a massive negative reaction (in the first year) to a particular blood pressure pill ... (The worry) absolutely terrifying, absolutely terrifying ... (father) and I were canvassing other consultants because the (hospital) couldn't just seem to get on top of this. (MAnna, 28 RRT 12)

There was little time after the shock of diagnosis for parents to discuss the huge trauma to their lives, and little time to devote to sustaining their own marital relationships. Separation of roles, with one parent staying in hospital with the sick child and the other at work or at home, meant they rarely met. Some had little financial capital and/or little social network capital and this exacerbated an already challenging situation. Equally, the relative youth of most parents (most interviewees had been a first child), made it more difficult to manage what was probably the biggest challenge of their lives.

The marriages of some early onset parents survived this upheaval, but it placed great strains on their relationships.

The only way we could each control our own ... pain was to run parallel to each other ... we talked about the logistics, about the medical, about the practicalities, but we couldn't share each others' grief ... I felt I was having to carry the whole load ... and he was having the most ... horrendous problems, because he was having to work and carry the load, and not be there ... I think we both felt that ... each was carrying a bigger load than the other. (MAnna, 28 RRT 12)

The (psychologist) thought that we had a strong relationship, we seemed to be fighting it together ... we would discuss it ... and then we'd make a decision ... We were very lucky ... with each other, and we do listen to each other, although it's more my side than his, but ... it's give and take. (MJames, 16 RRT 12)

The stress and anxiety all parents experienced initially, and over time, possibly affected the physical and mental health of several.

I have had nothing but ill health for the last 7 years ... now I've got this illness on top of everything else, this lupus, which weakens me, distresses me, and can't be cured. (MOliver, 26, RRT 7)

I am overweight ... I'm diabetic. (MTristram, 29 RRT 5)
Family breakdown
The marriages of most early onset (CKD or ERF) interviewees' parents (12) broke
down sooner or later, and the mothers (in most cases) were left with limited income
(Appendix 3, Table 20). All the interviewees whose parents had separated were
living, or had lived, with their mothers, except Amy who had lived with her father, and
Marc who alternated between parents. Several husbands had been violent and/or
had drink problems, and the data suggested that some fathers simply could not cope.

I got depressed because I was virtually on my own with Tristram all the time. His Dad
wasn't a very good person ... I was married to him for 5 years, but he used to drink a
lot and ... knock me around quite a bit. (MTristram, 29 RRT 5)

We were alright when we were first married, but he had a drink problem... Soon after
our daughter was born ... he'd wasted our money, and I was back in my parent's
home with my dying father. (MOliver, 26 RRT 7)

Few early onset interviewees were ready to suggest that their illness might have
contributed to their parents' divorce/separation, and for many their early childhood
was a long time ago. Similarly, few mothers wanted to attribute the family breakdown
directly to the interviewees' illness. In all cases, the 'real' reasons were hard to
ascertain, but ERF appeared to be an important contributory factor.

When I got ill (my 2nd sister) was a little baby, so that put a massive amount of strain
on my parents. ... that's not to say that I blame my kidney failure for the divorce or
anything. (Daniel, 27 RRT10)

They split up ... probably just about the time that I was ill... nothing to do with the fact
that I was ill... I was about 5 or 6. (Marc, 30 RRT 10)

I think ... I got tired of him (my husband).... I don't think it was (L's illness), but it could
have been ... you devote all your time to your child; you haven't got time for anything
else. (MLuther, 27 RRT 6)

Amongst those who were older when they first became seriously ill, few talked about
the impact on their families, beyond the immediate disruption to their lives, and none
mentioned that their parents had separated. Similarly, their mothers spoke only of
the shock and disruption, how the 'burden' was shared, and how they had coped.

I feel that I do (carry the burden), whether or not I do ... I know her Dad ... worries
about it, but he doesn't ... talk about it. (MMarian, 19 RRT 16)

Overall it appears that having a child with ERF put more strain on parental
relationships that were relatively new, in which the parents were relatively young.
6.4.2. Effect on siblings

Several siblings were seriously affected, especially those close in age, and some difficulties persisted into adult life. All except four of the prepubertal onset interviewees had younger siblings, who were highly dependent on their mothers’ care.

The middle one got really completely neglected ... she lost out, all the way ... we did things to compensate for that later. (The youngest) didn’t really notice. (MAnna 28 RRT 12)

The impact on siblings was greatest where there were other constraints, such as living in a one parent household, and sibling relationships were seriously affected in at least two families. Managing ERF made time short for looking after younger siblings, and the need to earn money competed with time available to care for the children. One family provides an ‘extreme case’ of sibling distress: Luther’s much younger half sister had spent much of her early life with her mother in hospital with Luther, as there was no one to look after her at home. She had developed serious mental health problems at the time of the interview (aged 16).

I used to just drag her along (to the hospital every day). It were easier ... instead of leaving her and worrying ... Her whole life has (been affected) ... she’s never been able to really bond ... with friends ... her schoolwork has been affected ... she’s being bullied ... We took her out of school and she had home tuition ... everything went to pieces ... she isolates herself ... she’s lost friends now, ‘cos she’s not at school ... She runs off in her bedroom and hides when people come to see her ... the counsellor comes here, ‘cos she won’t go ... she’ll only talk to a certain few ... not even my Mum very much. (MLuther, 27 RRT 6)

Mum... was trying to juggle her work ... she’d have me on the telephone crying for her to come and be with me, and (my brother) on the telephone, crying for her to go home ... to him ... and it affected ... my relationship (him) for a long, long time. (Marc, 30 RRT10)

Older siblings were also affected.

My sister (older) has been left out... she doesn’t really talk about it... it’s made an impact on her ... I can see it has. (Kieren, 29 RRT 7)

My (father was abroad) ... and my brother was... kind of the father at some stage, he’s 10 years older than me, (when) he went through ... teenagehood, he didn’t get ... much of it. (Alice, 24 RRT 9)

For later onset families, there were fewer problems and these were mostly related to resentment about the time and attention devoted to the sick adolescent. Older siblings in some families contributed to caring for younger siblings, especially where all the siblings were adolescents/young adults.
They've been brilliant with her ... but she's like the baby sister. (MMarian, 19 RRT 16)

His brother ... it were difficult for him ... he didn't get as much attention ... I think he were resentful sometimes. (MLuc, 24 RRT 18)

Overall, the onset of ERF challenged family relationships for the early onset interviewees more than the late onset interviewees. For the worst affected, parental relationships broke down and sibling relationships suffered lasting damage.

6.4.3. Social and cultural capital in family

Financial capital
There were extra financial demands on the families from the time of diagnosis. These began with the cost of travel to distant paediatric units, and costs associated with staying overnight away from home. After hospital discharge, there were the ongoing expenses of frequent travel to hospital and the special 'renal' diet. For some families, a car became vital where one had not been before, whether this was because of the poor health and weakness of the interviewee, or because of the time taken to travel long distances frequently to the paediatric hospital, or even school.

Many of the interviewees' mothers had been working, either part time or full time, when the interviewee became ill, but gave up work. Both working and middle class families were financially 'stretched', and it was possible that, while some managed, financial worries had contributed to breakdown of some early onset interviewees' parents' marriages.

Financially we made sure we were OK ... (but) I gave up my job to look after to look after her... I was working in school 3 days a week. (MCarmen, 24 RRT 15)

It wasn't that I lost money directly ... we had to get a second car. (Mum) had to get the kids to school ... (and I) to get Daniel to hospital and back. (DDaniel, 27 RRT 10)

He was poorly right from day one... until then I was working ... after I didn't get chance to go back. I used to have little part-time jobs, like cleaning. ... When he got a bit older ... my Mum and Dad used to look after him, and I worked in a hotel. (MTristam, 29 RRT 5)

(Mum) had to ... work as a temp, trying to pick up work wherever she could ... It was a nightmare for her ... when she tried to apply for some kind of benefit, she was offered £3 a week ... It was a case of fighting tooth and nail through the courts to get money from my father. (Marc, 30 RRT10)

James' family experienced extreme and enduring hardship, because his father was not earning enough to manage the extra costs and support the family (3 children), and their rented accommodation was too small to accommodate PD. Eventually, they
fought 'the authorities', were re-housed, and obtained the level of statutory support and resources to which they were entitled.

_We was just racking up ... debt after debt ... we weren't even living 'hand to mouth' because we didn't even have that... we were literally living on credit ... we got a wheel chair to take him to school ... because we couldn't afford to put the petrol in the car ... it was a case of, 'Do we eat or do I put petrol in the car? ...We applied for (DLA), they refused. I appealed, we lost that ... (eventually) we went to a tribunal ... and (the chairman) said, 'This family shouldn't be here ... this should have been granted first time'. (MJames, 16, RRT 12)_

Those with higher income found the extra financial burden of illness manageable, and used their financial resources to help lessen the impact of the illness on the rest of the family. Professionally employed/self-employed fathers had been able to take time off to support the family without financial penalty. One or two families were able to fund extra child care, private tutoring, private schooling, and improvements to their home.

_We had a nanny (again) when Anna was diagnosed ... because (after Tx) she wanted to go back to (the school) where she had been, that involved private tutoring ... We were really lucky ... being... able to afford it, (MAnna, 28 RRT 12)._

_'Cos I was on CAPD ... we did this extension on the house ... I've got almost my own flat ... nearly self-contained ... a settee, bed, office and ... bathroom (Jude, 22 RRT 10)._

Thus the overall financial impact depended what financial resources were available to the family, and those with few financial resources, especially in the prepubertal onset group experienced serious financial hardship. Many families had been dependent on two incomes, and managing financially was harder when the mother became unable to work and/or if marital breakdown occurred.

_Social network capital_

Social network capital was an important resource for affected families from diagnosis onwards, particularly where the interviewee was ill in early childhood, and had younger sibling/s. Where the interviewee's family was part of a large extended family living nearby, the family helped to look after any siblings, whilst the mother stayed in hospital with the sick child, and the father went to work. The wider family also provided mothers some respite from fulltime 'hospitalisation'.

_Aunts and uncles live 2 minutes down the road ... my sister was kind of passed from pillar ... she'd come in from school not knowing who was cooking her dinner. (Carmen, 24 RRT15)_
(Dad) used to be two weeks away ... someone would have to pick my sister up from school ... the whole family both sides ... lives in the same area ... there was plenty of people around. (Jerry, 25 RRT 12)

Families where blood relations on both sides lived far away, found it harder to manage, and some found that friends were not as helpful as they might have expected.

(My ex wife) had ... 2 or 3 close, apparently close friends, living nearby, who appeared nowhere at all. Our parents (lived far way) ... so they ... couldn't come up and give her any support at all, so support just disappeared ... which doesn't help either. (Daniel, 27 RRT 10)

My parents (in distant local authority X) ... got a wheelchair for us, because no one was helping us. (MJames, 16 RRT 12)

Several mothers reported how they had little time to sustain their own friendships, and lost contact with some friends. Not only was finding time to socialise difficult, it was also difficult to repay any help in kind and some lost the social network benefits of being in work. These factors diminished the number of people some parents could call on for practical help in emergency.

I don't have a lot (of friends) ... the trials of dialysis ... cut down everything. People ... don't understand ... it embarrasses people ... (and) people think you're imagining things, 'cos they can't see anything. (MGeorge, 29 RRT 18)

We've found over the years, that friends have just dropped us ... we don't want to burden them (friends) with everything, but if they'd just phone and show a bit of compassion. (MTanya, 28 RRT 11)

One mother felt unable to talk to friends about 'things' lest she was overwhelmed by their negative responses. In addition, she/the family became labelled:

We got a label. We were the parents of THE child, so every single conversation, every single time you met anybody, that was the first thing ... even now ... people say to me, 'How's Anna, kidney's still all right?' ... that I hate. (MAnna, 28 RRT 12)

Again, where the interviewees had been ill from early childhood, some families were more adversely affected by limitations in the availability of social network capital than others, not all families had close relatives nearby, and others were disadvantaged because of the impact of ERF on their own social networks. This meant they had fewer friends and alternative sources of support and accumulated further disadvantage.
Cultural capital and social class

Little information about the social class of the interviewees' families was available directly. The range of occupations of both interviewees and their parents, where ascertainable, is appended in (Appendix 3, Table 23). Parental housing data were not available for those who lived independently, unless the parental home had been visited. Five interviewees lived with parent/s in rented accommodation (James, Luther, Oliver, Sara, Tristram), but only James lived with both parents. These families might be described as working class, as might some of those who were living in ex local authority housing (Debra, Eugene, Kelly, Lucy, Petra, and possibly George and Millie). Some families were clearly professional middle class families (Anna, Cecile, Daniel, Edward, Hanna, Gus, Marc, Samuel), and some were in business (Ajay, Jude, Tanya, and Satish), but the absence of data made it hard to categorise all of them.

The more middle class families used their cultural capital in their dealings with 'fellow professionals' in the NHS to optimise their children's care. They drew on shared professional code/s of conduct, reassuring staff that they were dealing with people, like themselves, who 'knew the rules'. Such parents arranged hospital stays, clinic appointments, and influenced treatment decisions to try to support family life as 'normal'; they postponed going onto the kidney transplant list, to fit in with important educational milestones, and biopsies deemed 'unnecessary'.

*They say, 'Oh we need an ultrasound'. My dad said, 'She did one last week ... can't you send the results?' Obviously they're speechless, 'cos they know they can, but maybe they just can't be bothered ... and I don't want to miss school just to do an ultrasound a week later at another hospital.* (Hanna11, 18 RRT 17)

Parental knowledge levels re the balance of risk and benefit in any treatment varied enormously. Several middle class parents were especially well-informed and, in time, became 'expert' advocates for their children. They talked about how they had successfully challenged staff about their performance, and had been successful in achieving extra information that was beneficial for the everyday management of their child's health/disease.

*(We) were regarded as hugely interfering ... the doctors said they were too busy to talk, so we got them to make an appointment. We used to question everything ..., we'd insist on being in meetings, we'd insist on Anna knowing what was going on.* (MAnna, 28 RRT 12)

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11 Hanna's disease was inherited, and her father had a functioning renal transplant
My dad said, 'We'll do the (haemoglobin) today ... I'm sure it's better'... the surgeon will say, 'If it's 11, we'll postpone it (dialysis)'. And it was 11. My Dad ... (says) we don't want you to start dialysis (yet)... 'cos I'm still doing my studies ... every time, I think it's so funny ... how my Dad always bargains with him. (Hanna, 18 RRT 17)

However, professional attitudes had alienated two middle class families who then took advice from alternative health professionals. This proved injurious to both adolescents' health from a clinical perspective (Henry and Gus), and jeopardized the life of one. However, both interviewees perceived it as beneficial overall, because it offered them more autonomy and delayed the start of RRT.

He said (to my Mum), 'If you were a doctor I could explain it to you', and he didn't bother. ... The trouble with the doctors started after about 2 weeks in hospital ... I went to homeopath... went to an acupuncturist ... then I found this ... it's like a remote control thing which vibrates, and it definitely helped, it was kind of keeping me (off dialysis). (Gus, 25 ERF 19, RRT 22)

Middle class families appeared to be more knowledgeable about education than working class families, and kept their high aspirations for their children in spite of their illness. This manifested itself in being less satisfied with the hospital schooling and other alternative educational provision. Anna's mother contrasted her attitude to that of 'other' families, who appeared to be more indulgent towards their child, wanting to compensate for their illness by 'spoil[ing]' them; however, holding high aspirations, with hindsight led to some self-doubt.

The (other) parents said, 'Well he's sick, and therefore he should be allowed to do what he likes'. You see the opposite attitude for us, 'You're sick, but that's not changing anything' ... the least we could do was to keep her ... with all the aspirations and the hopes, and the advantages, that we could give her ... I'm sure we must have pushed her, but ... on the other side was Anna's need ... to appear normal and go on being normal ... She never really said, 'I'm not doing this, or this isn't right, or I'm too tired'. (MAnna, 28 RRT 12)

Parents with less cultural capital appeared less confident in their interactions with hospital professionals and some found they were not taken seriously. They were fearful of questioning expert opinion, with some justification, and being treated as 'stupid'. Evidence suggested that working class families were less interested in becoming independently knowledgeable about ERF in order to monitor or scrutinise health services, but possibly more interested in seeking support and sharing experiences via internet patient sites.

Other parents ... (said) 'Well I don't understand why they've changed the drugs'. You'd say, 'Well go and ask them', but (they'd say), 'No, I can't do that'. (MAnna, 28 RRT 12)
My Mum came, because we were really worried. When we got to the hospital, it was a young lady doctor, and I said ‘He keeps weeing and it was like cold tea’... she just said, ‘You’re just wasting our time, you’re an hysterical mother’. (MTristram, 29 RRT 5)

(I use an internet) chat room to find out about FSGS from other patients... the official stuff doesn’t give you nitty gritty, and it’s people’s stories and how they deal with it which makes it easier for you to deal with ... I used to go on it ‘cos I couldn’t sleep at night, then I found (this) by accident. (MJames, 16 RRT 12)

Overall, these data show how middle class cultural capital was often valuable in managing the challenges of dealing with qualified hospital professional staff, and mitigating the impact of ERF on the child and family. Those with less cultural capital appeared to be more at risk of getting a less child and family-friendly service because they had to fight harder to establish themselves as credible.

6.4.4. Conclusions social resources in childhood and adolescence
The immediacy of the challenges faced by the interviewees’ families when their child reached ERF, especially the urgency with which they needed to address looking after a sick child in hospital, as well as looking after the rest of the family, meant they focused on the task of limiting the impact of ERF on family life. What made a difference was the age of the interviewee at ‘end stage’ and the amount of social capital available to them.

The marriages of twelve interviewees’ parents broke down. All involved parents of interviewees who had been seriously ill very early in life, and most of these parents were relatively ‘young’ adults at the time. Thus many of the interviewees who presented with ERF in early childhood grew up in single parent families, with the associated adverse socio-economic costs. Where there was no family breakdown in the prepubertal onset group, and for all of the later onset group, the intact family remained as a major resource for their children.

All the families needed extra social resources to manage the impact of a child with ERF, but more were needed if the interviewee (and any siblings) were very young when they became seriously ill and/or in ERF. However, some family resources became depleted when they were most needed, not only by family breakdown, but also, because gendered social roles meant that fathers continued working, and most mothers gave up work. This reduced mothers’ access to social networks and added to financial stresses. High levels of cultural capital were useful in optimising the families’ experiences of statutory services.
6.5. SUMMARY

Analysis of data pertaining to the lived experience of ERF in the early lifecourse has focused in this chapter on disruption to the education and family life of the study participants. Both survey data and interview data from patients and parents have been used to create a detailed picture of the impact of biographical disruption in the interviewees' so called ‘formative’ years.

6.5.1. Critical moments

The concept of a ‘critical’ or ‘fateful’ moment (Giddens, 1991; Thomson, Bell, Holland et al., 2002) proved useful in bringing greater understanding to how personal choice and social structures shaped the lives of the study participants. During the early years of the interviewees’ lives, a succession of such ‘critical moments’, caused by serious ill health, disrupted their life trajectory, and exerted a significant impact on the rest of their lives.

For both educational outcomes and development of normal peer relationships, the beginning of each school year, and more importantly, starting a new school were critical moments. Evidence showed that these times were more critical for the prepubertal group, because they were at an earlier stage in their educational and social development, and were absent from school for more of such critical ‘moments’; Most of the postpubertal group experienced fewer critical moments and they occurred when were more mature. They had already established a firmer educational base, had more established friendship groups, and a more secure emerging adult identity.

External examination times were also critical moments for participants. All interviewees who were ill just before, or during, their GCSEs or A levels, suffered serious setbacks, both academically, and socially; socially, because they became separated from their peers, if the latter were more successful. The structural constraints of normal educational provision, albeit partially addressed by hospital schooling and the home tuition services, appeared to be insufficient to accommodate the particular needs of those with ERF. Post-16 education funding was not flexible to accommodate the needs of those who still wished to obtain basic educational qualifications in their late twenties.

6.5.2. Embodiment and peer relationships

The data demonstrated clearly how the embodiment of ERF played an important role in the lived experience of all of the interviewees. RRT technologies, their invisible
obtrusiveness and their side effects, increasingly made all the interviewees feel very
different from their normal peers. The immediate impact of transplantation caused
sudden visible changes in their facial appearance and gross changes of body shape.

Over time, interviewees' bodies continually changed, as an increasingly wide range of
technologies (medicines, grafted organs, tubes, catheters, etc) were needed to keep
them well and stable on RRT. Some of the changes were due to the largely invisible
side effects of RRT (susceptibility to cancer, heart disease and brittle bones), and
some to the more visible, but normally 'hidden from view', presence of catheters,
fistulas, body scars and/or abdominal distension.

For many of the prepubertal onset interviewees, the legacy of early ERF manifested
itself in failure to grow normally, and relative physical and sexual immaturity at
puberty, compared with their peers. The effects of these differences were
experienced keenly, but more male interviewees than female interviewees were
adversely affected by small stature, especially its limiting effect on their participation
in sporting activity and social relationships with peers.

6.5.3. Identity development

Identity has proved to be a crucial concept in understanding the meaning of chronic
illness (Charmaz, 1983), and for the interviewees, the development of a secure
positive adult identity was affected by the timing of the onset of ERF, the ensuing
trajectory of life on RRT, and the embodiment of the condition. Feeling different from
their peers, being stigmatised by peers, and perceived discrimination by adults and
teachers at school, appeared to contribute to making it especially difficult for the early
onset interviewees to develop a positive sense of self. All adolescent interviewees
found it harder to join in peer group activities; but males were most affected, because
masculine practices of drinking alcohol in clubs, pubs, and bars were injurious to RRT
technologies.

The data showed that while several prepubertal interviewees had clearly been self
confident individuals in adolescence, they were of relatively normal height for their
age, had been successful at school academically, or in sport, and had perhaps
derived a positive sense of self from these successes and accumulating social
resources. The majority of the prepubertal interviewees remained smaller than
average in stature, remained immature longer, and had experienced a range of peer
relationship and academic problems at school. For them, performing 'age identity'
was an issue in the wider world after adolescence.
The postpubertal onset interviewees, on the whole, were less affected by others’ negative judgments and assumptions during their early years at school, and it could be argued that their early life experiences had, for most (except those with renal problems at birth), enabled them to develop a positive emerging adult social identity, before they became ill. All were of normal height, except one female interviewee, whose whole family were small. After diagnosis, they experienced the stigma of being ill, and suffered the shame of looking unnaturally obese after transplantation, but most had benefited from improved transplant treatment technologies, had fewer side effects, and experienced fewer of the ‘yoyo’ swings between RRT modalities.

6.5.4. Social resources
The data demonstrated clearly that social resources played an important role in mitigating, on the one hand, or exacerbating, on the other, the impact of disruption to the early lifecourse caused by ERF. Again, the age of first presentation with ERF was important, in that where interviewees were ill early in childhood more demands were made on their family’s resources, and these demands more often exceeded the social capital available to the family. In all families, it was advantageous to have higher levels of financial, social network and cultural capital, but the social capital inherent in an intact family structure, was reduced for many prepubertal onset families, when fathers (mostly) left home leaving mothers in difficult socioeconomic circumstances as single parents.

6.5.5. Summary
The data suggest that more prepubertal onset interviewees on RRT left school with lower or delayed educational achievement, and had less success in forming positive relationships with their peers, than those who became ill at puberty or later, and that in part, both of these effects might be attributable to the age at which they became ill, and the embodiment of ERF. Some effects related to embodiment were relevant to all ages of onset, but early onset made a difference to the physiological and social maturity of the prepubertal group, making adolescent identity development particularly difficult.

Where families had more cultural, network and financial capital, they were better able to mitigate some of the overall effects of having a child with ERF. There was a marked difference between the early and late onset interviewees’ families in terms of how parental relationship breakdown affected the overall resources of the prepubertal onset group disproportionately.
Overall, interviewees' eventual educational outcomes, and their success in forming and sustaining peer relationships, influenced whether they had established a positive sense of self, to carry forward into their adult years. Low levels of social capital in the family, combined with poorer educational outcomes, and insecure adult identities, disadvantaged the more working class interviewees, especially if they were male and ill in early childhood.
7. EMERGING ADULTHOOD, EMPLOYMENT AND SOCIAL IDENTITY

7.1. INTRODUCTION

This chapter explores how the uncertainties of renal replacement therapies (RRT) affect employment and continuing identity development in emerging adulthood (Arnett, 2001). It considers how the relative invisibility of ERF as a disease affecting young people in society, and the general lack of public understanding of the function of the kidneys, affects their experiences. It also examines how far concepts associated with normal and disadvantaged youth transition into adulthood, such as independence, choice and agency, apply to young adults with chronic illness and continues to explore the particular role that social resources play in mediating the impact of the resultant social disadvantage.

7.2. AUTONOMY AND INDEPENDENCE

The identity work the interviewees began in adolescence continued into emerging adulthood, and the drive to become independent of their parents and other powerful adults, and exert control over their own lives, contributed to developing a positive sense of self as an adult. Small things like learning to drive made an early contribution to the independence and self confidence of some interviewees. They described how driving gave them a sense of achievement, more choice about how they spent their time, and, for peer relationships, a non-discrediting excuse for not drinking alcohol to excess.

*My grandparents ... bought me this old (car) ... 'cos I couldn't walk anywhere ... It was something... I'd achieved as well ... getting a driver's licence.* (Henry, 30 RRT 19)

*(Driving) that's a big part of my life, a big part of one's independence ... It's very important to me; I don't think I could do without my car.* (Wayne, 20 RRT 15)

However, some of the confidence that driving brought could be marred by issues related to developmental delay and age identity. Jude was so small that his head was not easily visible above the car seat from behind.

*It's got me down a little bit now and again ... I didn't really care in bars, because a lot of people got ID-ed, but ... driving ... people would be pointing and staring, or slowing down to keep up with me, it was very, very off-putting.* (Jude, 22 RRT 10)

However, in more important areas, becoming independent presented greater challenges, especially where the legacy of illness in childhood or adolescence had
made the interviewees more than usually dependent on powerful adults, including hospital staff and their parents.

### 7.2.1. Continuing health uncertainty

Just over half of survey respondents said their future plans had been upset by having renal failure (Appendix 3, Table 24), as did 26 interviewees. There were proportionally fewer (10/22) of those beginning RRT at 0-10 years, and proportionally more (16/18) who began RRT at 11 years and over (Appendix 3, Table 25). These data suggest that many of early onset interviewees, who had experienced repeated disruptions to their lives by the time they became young adults, had stopped making plans for the future in the face of such uncertainty. For example, 17/22 who started RRT before they were 11, had lost one or more kidney grafts (Appendix 3, Table 7). Certainly, several academically able early onset interviewees had settled for employment that was ‘good enough’, rather than try to realise earlier higher ambitions.

*I'd got interested in politics, in ... trying to make a difference ... literature, books ... are the one thing I am ... passionate about ... I'll be happy with the small amount that I get from going into a library. (Marc, 30 RRT 10)*

*I'm not going to go for the graduate position training, that's 2-3 year thing and they're (employers) not take you on for 3 years ... you have to be selective. (Edward, 30 RRT 7)*

*It's that unpredictability that makes it very difficult to commit yourself to any sort of regular work ... I'm employed but doing 'permitted work' ... as and when it suits me. (Ben, 29 RRT 5)*

Several early onset interviewees were facing transplant loss, or retransplantation, when they were interviewed, and were, like Daniel, shocked to become ill again after a very long period of reasonable health. In this respect they were more like the postpubertal interviewees, almost all of whom had well formulated future plans when ERF came as a shock in early adulthood. For most of them, their plans became impossible after the advent/reoccurrence of ERF.

*The thing is with renal failure ... you get huge expanses of time where everything is absolutely fine ... it just doesn't register on a sort of interfering with your life ... (then) you often get the shock of it all starting again, again and again. ... I was (living abroad when they told me) and I couldn't go back for 5 months ... I was sleeping on the floor, I couldn't work, I was at hospital all the time, they couldn't tell me what was going on, they didn't know, they were just trying to re-establish this and this ... that 5 months was pretty (terrible). (Daniel, 27 RRT 10)*
I'd finished college and was just about to start my career ... (ERF) put a halt to all that really ... I'd been going to ... auditions and wondering ... why I ... couldn’t quite ... (be) quick enough. (Laura, 30 RRT 19)

The interviewees' survey responses showed that almost half of those asked (10/23) said their illness had made them worry about the future (Appendix 3, Table 26), as did half of all survey respondents (Appendix 3, Table 24). However, few interviewees talked directly about their fears of further illness, losing their transplant, or more general worries about their future lives; many more talked about the need to 'get on with life' and make the best of things.

I worry a lot about how uncertain my future is, and if I'm going to end up with more serious illness ... being educated, able to work, able to get an income, able to move house ... Every aspect you can think of bothers me, but I try not to think about it too much. (Wayne, 20 RRT 15)

I just try and get on with my life ... what's left of it. (James, 16 RRT 12)

You need to get on with things, there's no point in dwelling on them. (Ajay, 28 RRT 17)

7.2.2. Bounded agency

The importance study participants attached to being able to exercise control over their health was illustrated by survey data which showed that about two thirds of respondents (Appendix 3, Table 27), and almost three-quarters of interviewees (Appendix 3, Table 28), said such control was important.

It's something that you don't know, you don't have control of, it's a very, very primal basic fear ... You do feel better about things when you're in control, and you know what's going on ... what your results are ... why things are doing that. (Ben, 29 RRT 5)

I'm a complete believer in fate ... I have no control over my own life, as far as I'm concerned ... I know I should do, but I just don't. (Tanya, 28 RRT 11)

I like to know what's going on with me, I think it's a certain sense of retaining self control over what's happening to you... and I like to have my life in order. (Anna, 28 RRT 12)

Whereas most chronically ill adults are encouraged to manage their own illness soon after diagnosis, as were most of the post 16 onset interviewees, most of the prepubertal interviewees had only been 'granted' control when powerful others (parents and/or NHS staff) decided they were ready. Some remembered feeling powerless, some angry, about being told what to do at an age when they wanted to decide for themselves.
It's my health, my body ... I wanted to be ... in control of my own destiny ... I didn't like being dictated to ... particularly from those type of consultants. ... Ultimately we all do have a choice ... we can always top ourselves. (Henry, 30 RRT 19)

Others, in contrast, worried about taking over responsibility for managing their care from their parents, in a situation where making mistakes, or simply forgetting to take their medication, could lead to loss of a precious kidney graft or even be life-threatening.

I just hated it (adult clinic) because it's all about relying on yourself and stuff. (Sara, 27 RRT 2)

I've gone over to my girlfriend's ... but then had to come home... because I forgot to take tablets ... I've even got tablets at hers because ... we had to travel to my house at midnight in the snow because of tablets. (Matthew, 24 RRT 14)

Most prepubertal onset interviewees' parents found it hard to relinquish the dominant roles they had had when the interviewees were younger, and worried that the interviewees would not take adequate care of themselves. Over time, they were persuaded, sometimes by interviewees themselves, sometimes by hospital staff, to become less closely involved in the interviewees' clinical care.

... (Mum) would say, 'There's this, this, and there's this' ... I would sit there, squirming ... that might have been part of me instigating saying ... 'I'll go on my own', just to make life easier for myself. (Marc, 30 RRT 10)

Later onset interviewees took responsibility for managing their illness from the start, although their parents still worried.

I said to her last week, 'Have you got enough ...tablets?'. 'Yes, Mum'. She says it sarcastically, but ... I thought that was something she needed to manage right from the word go. (MMarian, 19 RRT 16)

However, they felt equally powerless, with little agency over their health, other than 'monitoring' the quality of care they received, and challenging hospital staff.

I think having control definitely ... so you don't feel so powerless. Really... there is only so much you can do ... there's no stopping it from getting worse. (Hanna, 18 RRT 17)

Exerting agency

Some interviewees were cautious about making any decisions about their health and taking any risks at all, but others took measured risks, professing confidence in their own judgment. Some took serious risks with apparently no adverse effect.

I was given a kidney guard ... elastic things placed aroundblah, blah, which I think I wore once, it was so damned uncomfortable I never wore it again. (Anna, 28 RRT 12)
I can guarantee I did binge drink ... but it put me in good stead ... I think I know my own body and I know my limits, I don't think anyone knows me better than I know my body. (Carmen, 24 RRT 15)

The greatest risk from a renal health perspective was to ignore medical advice completely, and for those living with transplants, this meant not taking their immunosuppressive medication. For those on dialysis, it meant missing dialysis and/or ignoring fluid intake restrictions. Samuel had missed dialysis for 4 days, and Marc had not taken his medication but kept his transplant.

At the end of that 4 days in (abroad), I was feeling ... quite bad. I'd controlled my fluid impeccably, but I hadn't starved myself so I was eating, and the toxins were building up ... I wasn't ill ... but I wasn't feeling like I'm feeling now. (Samuel, 28 RRT 17)

I was ... pretty bad with missing drugs ... I was very, very lucky ... much later on, I stopped going to hospital, I didn't go to any check ups for about 4 years. (Marc, 30 RRT 10)

Others who had missed medication repeatedly when they were younger were not as lucky and had lost their transplants; although Alice and Daniel were still indignant about accusations of non-compliance. Adult physicians took a punitive approach to transplant loss through 'non-compliance', and Alice and Kieren felt they had been refused access to the transplant waiting list for this reason.

Because of my non-compliance they took me off the list for a year, which I didn't really agree with, but, that's their policy ... I found out that a kidney did come up ... obviously I couldn't have it. (Kieren, 29 RRT 7)

7.2.3. Loss of child-centred care

Transition into adult renal services was a first step into independent adulthood for most interviewees. Although this transition has been acknowledged by renal services to be difficult, in one sense it was easy as the interviewees were familiar with talking about their clinical history, and knew how to present themselves in a hospital environment, knew the rules for social interaction and were used to following them. However, as adults they were expected to take responsibility for their own health care and manage their own treatment. Parental involvement was actively discouraged.

The main challenges interviewees faced in entering adult renal care related to losing the holistic quality of the care they had been accustomed to in paediatric units, and its replacement by adult care which most found impersonal, and some even brutal.

You see different people and are 'in and out' ... I don't see the same doctor, I don't feel like I can really confide ... I told (one) I was on antidepressants he didn't really
make anything of it ... but it had been a massive thing for me ... So I didn't bring it up again. (Tanya, 28 RRT 11)

In addition, any hopes of continuing to be 'well' or live a normal life, in the longer term, were 'dashed' by seeing much older sicker renal patients at clinic: people who were not well enough to live normal lives, not well enough to be working, and whose lives appeared to have followed a 'downward' trajectory since they had become ill.

In front of your face ... the side effects of some of the illnesses that they've got on top of renal failure, some of the side effects of renal failure ... just puts the fear of God up you. (Jude, 22 RRT 10)

When I go to clinic, I'm maybe the only one of about ... 10 people that actually work. I don't think there are many people with renal failure that are able to work. (Sara, 27 RRT 2)

There were rarely other young adult inpatients on the renal wards, and most interviewees found themselves surrounded by very elderly, often terminally ill patients, some with so-called 'dialysis dementia' (associated with long-term dialysis).

Straight into adult ... all the people on my ward, were 70, 60 years older than me (Marian, 19 RRT 16).

The first time ... it was a nightmare, I absolutely hated it ... I felt as if ... I wasn't worth looking after ... I needed to do my work (studying) ... if I didn't get my work in ... life wasn't worth living ... and it wasn't taken into account (Amy, 24 RRT 7).

The dialysis unit was ... unbelievably depressing ... I just thought it was full of ... sort of corpses (Henry, 30 RRT 19).

The bleak pictures of possible future lives added to the traumas of transition from paediatric care, admission, and/or the shock of diagnosis. The evidence speaks for itself here, but includes young adults with relatively short and positive RRT experiences, those with long and complex clinical histories, and some who continued to find adult units difficult after 5 or more years' attendance. In spite of being in a familiar clinical environment, interviewees' positive sense of self was threatened by what they saw and experienced, and reinforcement of their identities as 'kidney patients' by the staff.

7.2.4. Insecure independence

Most interviewees were not ready for emotional independence; even those who were older and lived alone, saw their families as sources of support. Family support might gradually be expected to be replaced by support from friends or a partner, and 29 interviewees saw their friends as sources of support (Appendix 3, Table 29), but
fewer than might be expected had been talking about their feelings to friends (17/36) or family (22/37) (Appendix 3, Table 30).

Ten interviewees reported feeling depressed, 8 lonely, and 5, all early onset interviewees, feeling under social pressure to be positive (Appendix 3, Table 30). Interviewees' depression appeared to be under-diagnosed clinically, but manifested itself as withdrawal, lack of energy to change their lives, and/or as acute anxiety. It was present amongst those working, as well as those unemployed or 'underemployed', and in both early and late onset groups.

I've had occasions where I've sat in front of a box of tablets and thought, 'I wonder what would happen if I take the whole lot' ... I think any renal patient will have at some point. (Ben, 29 RRT 5)

I used to get quite down and cry (at Uni), but never thought anything of it... I was ... too busy having a good time ... (My illness) was something I would never really talk about... I found it quite hard to get really close to people ... I need to sort it out ... My kidney's all right, I just need to get on with it, but I can't. (Tanya, 28 RRT 11)

Several interviewees were dismissive or sceptical about psychological services and/or a need for emotional support, perhaps reflecting widespread stigmatisation of people with mental illness in society.

I was ... 9,10 ... some doctor decided it would be a good idea for me to see a psychiatrist or something ... I thought this is the biggest waste of time ever ... that was my ... full exposure to counselling or psychiatry. (Edward, 30 RRT 7)

Although several interviewees admitted they had benefited from counselling in the past, only one said she was having counselling in her interview and the majority of interviewees had never joined face to face kidney support groups (only 4 were in their local Kidney Patients' Association). Most were clear that they did not want support from other patients, especially older patients, or to make friends with their peers with ERF; they wanted 'normal' friends and eschewed those who were ill.

(KPAs) are often run by people ... who are retired, and have this completely different agenda to the (people our age). (Edward, 30 RRT 7)

They (KPAs) are all just ... focused on knowing what their creatinine is, what it was last time... how much water they've got to drink, I don't want to ... lump them all in together, but it does feel like that. (Sara, 27 RRT 2)

In addition, it was both upsetting and depressing when friends died.

(X) used to say, 'The only reason I set up (group Y) is cos I want someone ... to sort it out for me ... it's purely selfish', she used to say with a big smile ... she was feeling very isolated ... it was a necessity ... then of course (she) died. (Ben, 29 RRT 5)
The group of kids that I was in (paediatric hospital) with, I think I'm the only one left alive, which is a fairly sobering thought. (Anna, 28 RRT 12)

Alice, however, who heeded maternal advice to isolate herself from patient support groups, wondered whether she could be more involved in the KPA.

Mum ... (says), 'I want you to lead as normal life as possible', so she wants me NOT to get into (KPA) ... I do sometimes feel that I should ... we go, every year ... it's good to get the support, even those two days of the year (Alice, 24 RRT9).

7.2.5. Summary

Overall, the evidence demonstrates that many of the interviewees wanted to become independent, and exert agency over their lives and health, as emerging adults, but faced continuing uncertainty and worries about their future health. Exerting agency meant managing the tension between taking control of their health, and living with any adverse consequences that might ensue, especially from ignoring medical advice. They managed this balance differently, but all experienced only limited agency.

Transition into adult care meant that interviewees were expected to assume responsibility for their own health care, but were confronted by the reality of their future lives with ERF, and received little support from staff. Their need for autonomy coexisted with a need for continuing support from hospital staff, parents and, to a lesser extent, friends. Most did not seek support from their peers with ERF. A considerable number were depressed and their emotional support needs were perhaps likely to delay progress towards adult independence and separation from their parents.

7.3. TRANSITION INTO EMPLOYMENT

Gaining employment is an important step towards independence for emerging adults, and a foundation stone for a positive sense of self in adulthood. Study participants entered the employment market with very varied levels of educational attainment and maturity, and found an environment in which they were expected to be independent adults. Some who approached employment were educationally successful, but others had few qualifications.

7.3.1. Employment status

Forty one percent of study participants were employed fulltime, and fourteen percent part time (Appendix 3, Table 31). For comparison, UK unemployment rates for young
adults, aged 16-24 in 2008, were 11% for women without dependent children, and 15% for men without dependent children, and for those aged 25-34, 3% for women and 5% for men (ONS, 2009). Other data showed that 16.1% of all young people 18-24 in 2010 were not in education, employment or training (DfE, 2010). These data provide an indication of employment rates for all young adults just after the study.

**Key variables affecting employment**

Each interviewee’s occupation and employment status in relation to their age and education is described fully in Appendix 3, Table 32, Table 33, Table 34. These data reflect, as expected, the importance of education to gaining employment, and, as expected, that more older interviewees were working fulltime than younger interviewees. These data also show that a high number of older interviewees were neither working nor students.

Participants’ employment status in relation to modality and the age at which they began RRT is perhaps more important for this study. Survey data show that significantly more transplanted participants were working than dialysis participants, and that significantly fewer of the early onset group were in paid employment (57% v 76%, p=0.02) (Appendix 3, Table 31, Table 35).

Interview data below (Table 7.1) show that 13/15 interviewees working fulltime were living with a transplant, a high proportion of interviewees not working at all were on dialysis, and some interviewees combined part-time work with studying. Few of those first diagnosed with ERF at primary school were working full time, and only one of those who began RRT before they were seven.
Table 7.1 Age of onset, employment status and modality for interviewees, compiled from survey and interview data

<table>
<thead>
<tr>
<th>Age onset</th>
<th>Employment status and modality (transplant or dialysis)</th>
</tr>
</thead>
<tbody>
<tr>
<td>RRT (groups) (N)</td>
<td>Full time</td>
</tr>
<tr>
<td>0-4 (4)</td>
<td>Sara (T)</td>
</tr>
<tr>
<td>5-7 (7)</td>
<td>None</td>
</tr>
<tr>
<td>8-11 (11)</td>
<td>Daniel (T), Lucy (T), Jon (D), Marc (T), Tanya (T)</td>
</tr>
<tr>
<td>12-15 (7)</td>
<td>Anna (T), Mario (T), Matt (T), Carmen (T), Jerry (T)</td>
</tr>
<tr>
<td>Aged 16 or over (11)</td>
<td>Millie (T), Laura (T), Luc (T), Samuel (D)</td>
</tr>
<tr>
<td>Totals N</td>
<td>15</td>
</tr>
<tr>
<td>Gender</td>
<td>8M, 7F</td>
</tr>
<tr>
<td>Modality</td>
<td>2D, 13T</td>
</tr>
</tbody>
</table>

Key
* = under 21 at end of 2006 (N=5);
T = transplanted
D = on dialysis
√ = not well enough to work (N=5)
○ = students working part time (N=3)
□ = on temporary/short term contract

7.3.2. Access to employment: bounded agency

Almost all study participants thought it was important to be in paid work (Appendix 3, Table 36, Table 37), and recognised that employment was a fundamental part of their identity as emerging adults. However, social structuring of employment in the UK means that paid work is largely carried out in 'normal full time' working hours and is most economically performed by individuals able to make a commitment to this.
About 40% of survey respondents reported that ERF prevented them from doing the job they wanted, and made it harder to find any job at all (Appendix 3, Table 38), as did similar proportions of interviewees' (N=15/39) (N=14/39) (Appendix 3 Table 39). These data, taken with the high number in part time work and/or studying, suggest that finding work was challenging for many interviewees. Most interviewees talked about their difficulties in finding work, and how their choices were limited, by both educational achievement and health.

**Critical moments for employment**

At least three interviewees became ill just as they were entering the job market or soon after, these were critical moments, paralleling critical moments in education, when illness forced an immediate and abrupt change to their employment plans. Millie had started work in a solicitors' office, Luc had just got a job in a laboratory, and Laura planned to travel as a dancer on cruise ships; none was able to fulfil these roles, although all were working full time.

> I left (school) at Easter and started work straight away ... I used to think, 'I'm not well, there's something wrong with my body'. (Millie, 26 RRT 16)

> Pretty devastated ... I'd just finished college and was just about to start my career, so it kind of put a halt to all that really... I'd been going to dance festivals, auditions and wondering ... why I wasn't functioning properly. (Laura, 30 RRT 19)

> I'd left school (after A levels) ... I didn't know that I'd failed (my exams) at the time. (Luc, 24 RRT 18)

**Educational constraints**

As might be expected, a high level of educational achievement increased employment choice, but not all those with degrees could get a job in their chosen field, especially if their health was poor; and several had chosen to continue studying, some changing their academic course. The later onset group achieved expected GCSE passes, and the gap between their desired career goal and what was achievable was on the whole, less for than prepubertal onset group, thus they had more choices. However, some of the most able were frustrated by their ill health and its impact on their career.

> I'm lucky ... I'm at a relatively ... fairly senior level ... but I'm 28 and I have ambitions ... if I wasn't on dialysis I could see myself in 2 years time being a candidate for a CEO position ... I do not see that as anything that is possible, so it's frustrating (Samuel, 28 RRT 17).

> I started teacher training ... I did find it very tiring ... I think that's down to ... my situation ... I do get tired easier than maybe a normal 25 year old ... you're up and downstairs, you're in a classroom, you're on the go all the time ... but I still wanted to
work with children. I'm now a mentor (FT) in a secondary school. (Carmen, 24 RRT 15)

Further academic study appeared to offer 'something to do' if they were not well enough to work, which also contributed to future employability.

I've got 4 degrees ... I've worked quite hard to get stuff done... I've been fortunate enough to work in some fairly OK jobs. (Edward, 30 RRT 7)

More than ... (10 applications) ... (and) no interviews ... I thought, 'This isn't getting me anywhere ... I need a bit more experience', so I decided to do the Master's degree. (Jon, 27 RRT 8)

**Embodied constraints**
The interviewees recognised they were competing with healthy people in applying for any kind of advertised job they were qualified to perform. Moreover, as Edward observed, employees with ill health can be seen as an 'economic burden' and a risk to business success.

*There's the Discrimination Act ... but it's illogical for a business to employ people who are not going to be there half the time ... other people are going to suffer, the business is going to suffer... it's definitely difficult for a renal patient on dialysis to get a job ... even with a transplant, it's more difficult to get a job, a good job. (Edward, 30 RRT 7)*

*There're too many good dancers out there who are healthy ... once people know that there's a chance that you could be ill, I don't think they'd employ you and I wouldn't blame them. (Laura, 30 RRT 19)*

It was implicit, rather than explicit, in the way interviewees talked about their employment choices, that employment in sectors where their physical bodies were likely to be exposed or displayed, or play a 'physical' role, was not a possibility. Employment requiring physical fitness was undertaken by some interviewees, but generally not found to be sustainable. The vulnerability of the kidney graft (where present) in the abdomen, and general tiredness, were obstacles to undertaking physical work.

*I got a job in the warehouse ... they were piling more and more hours on ... (I got) more and more tired ... it began to affect my health ... I had to leave. (Jerry, 25 RRT 12)*

*I've got a transplant now the function isn't that great, so I don't always feel that energetic. (Ben, 29 RRT 5)*

Jude, with GCSEs, found both educational and embodied constraints restricted his employment opportunities. His work as a self-employed courier was tiring but
manageable, but he wanted to give it up because it was isolating. However, he felt he had very few choices.

I'm doing stupid hours ... (I) just feel really tired, so I'll need to take a few days off, to sort of recuperate ... I'm by myself all day, which is ... why I'll probably give it up ... But I'm not the most employable person in the world, because of my illness ... I know they can't take that into account, but I didn't get the best grades at school, I haven't got A levels and I haven't been to University, so the jobs that I'd want to do ... they probably wouldn't touch me. (Jude, 22 RRT 10)

Embodied constraints meant that few male interviewees with very low levels of educational achievement had any real employment choices, especially after transplant failure. They were most likely, when physically demanding work became too tiring, to become long-term unemployed, like Kieren and Tristram below.

I was working in a pub from ... 8 o'clock in the morning to 3 o'clock in the morning... long hours ... I gave everything up. I didn't really do anything. I tried ... (studying) but ... I didn't have the concentration. (Kieren, 29 RRT 7)

I worked at nights ... for a little bit ... lifting and stuff, I just couldn't cope, eventually I went to see my doctor ... he said, 'I'm going to have to sign you off, looking at you, and looking at results'. (Tristram, 29 RRT 5)

Five interviewees said were not well enough to work, but in reality only two were not: Petra, with epilepsy could not return to her previous work, and Luther, after a stroke was too unwell.

I'm a beautician and ... sports masseur ... I can't work from home, nobody will employ you, 'cos you're epileptic ... ( work? ) yea, 'cos it gets you out the house ... friends still ring me up and say, 'Excuse me, my back's bad' (Petra, 30 RRT 9, T)

7.3.3. Effects of constraints

Only Anna asserted that her health had made no difference initially, but clearly international travel for work created 'difficulties'.

I did my degree, and it was always kind of a given that I was going to go into some kind of IT... (My illness) never had an impact on it ... I went to Russia last year, and (for) carrying drugs, in and out of the country and I had to get a special letter typed up and ... register it in various places, they're so strict about things like that. (Anna, 28 RRT 12)

Underemployment
Almost all the interviewees in paid work had functioning transplants (Table 7.1), but even with a good transplant, they were more tired than expected. Some, notably, Daniel, Lucy and Laura clearly enjoyed their work, and appeared well adjusted to the constraints their illness had imposed.
I love my teaching, that's what I would have eventually done anyway. (Laura, 30 RRT 19)

Several well qualified interviewees worked full time on short term contracts; for male interviewees, these were more likely to be in business, finance or IT; and for females, administrative work in an office. The limitations of short term contract work are well known, and were a real concern for those able to work full time. Some interviewees perceived they were 'underemployed', and also felt that they wanted more job security, and more protection from unemployment, than the average young adult in society. This was possibly related to their difficulties in finding work and/or because they perceived they had a high need for benefits traditionally associated with permanent employment (sick pay, holiday pay, pension contributions etc). Some with emotional problems were 'underemployed' included Marc, who had 'down-sized', Sara and Tanya.

I tried to go back to work, and within about 6 months ... effectively I had a breakdown ... I was put on various antidepressants ... under a psychiatrist. (Marc, 30 RRT 10)

I've been with the agency for ... years now... I always know that I'll get good jobs ... I'm just missing out on all the benefits of having a permanent job ... I don't interview very well, I get very nervous, I know that can go against me ... I would have to work on that myself (Sara, 27 RRT 2)

I can't go and change my job, 'cos the idea of getting another job scares (me) ... it's not something I ever want to do really because ... I've got no confidence, and stuff like that. (Tanya, 28 RRT 11)

However, temporary work or short term contract work offered many advantages: entry was less competitive, there was no necessity to disclose health status, and with adequate social skills, most qualified interviewees found it easy to find temporary work. It was also easier to move in and out of work, as their health necessitated, and offered opportunities to prove themselves (hard working, reliable, competent), which, in turn, could lead to a permanent post. It also enabled them to put some work experience on their CVs.

I tend to only apply for permanent jobs whilst I'm actually in a job, because it looks better on the form if you're in a job rather than unemployed ... They're more willing to appreciate your skills ... knowing you've got them. (Sara, 27 RRT 2)

I'm on contract, I'm contracted out to work on another site and do the (IT) support for them. (Jerry, 25 RRT 12)

Self employment and family employment also offered several interviewees (3 or 4) the flexibility they needed to manage their work load at their own pace, with time to go to hospital appointments, and time to rest if unwell. Moreover, they avoided the
challenge of repeatedly beginning work in a new work place and having to prove themselves. However, it could be isolating, as Jude found.

Facing unemployment or unemployed
Some less qualified, and/or less academically able interviewees, found themselves unemployable because of the combined effect of their health and poor GCSE results, and several tried 'access to work' and/or access to education schemes. Two, Jon and Henry, were employed when interviewed, albeit insecurely, through Access to Work schemes. The limited employment choice some faced is exemplified by the contrasts between James' dreams and reality, between his choice, and his mother's evidence in relation to it.

I was looking forward to becoming a police officer ... going into the army or something ... that dream shattered ... the (Access) course is 22 weeks ... (then) I'm doing a construction course ... if I finish that I can get a licence or whatever in plastering. (James, 16 RRT 12)

(I said) 'You like driving ... that's something you could do ... you'd never be a poor taxi driver ... (but) he's picked one of the hardest things to do (construction) ... he normally shies away from physical work ... we can't see it. (MJames, 16 RRT 12)

I got in touch with (charity) ... part of a government initiative to get people who are on benefits, long-term disabled people ... back into work. They helped me. (Henry, 30 RRT 19)

(I said) 'I've had a difficult ... situation in the past where someone wanted to employ me and they didn't because of my illness ... I just want an opportunity to prove that I can work' ... they offered me the job. (Jon, 27 RRT 8)

Several younger interviewees did voluntary work and/or part time work and this had helped them get paid work. For others, temporary or part time work was invaluable for supplementing their benefit income.

I went to a computer shop ... just a voluntary thing ... (then at job interview) 'We can't offer you that job because you've not got the experience for it, but we can offer you another'. (Luc, 24 RRT 18)

I'm ... trying to get my GCSEs ... 2 days a week, so I've got time to do a bit of (paid) work and some voluntary work. (Wayne, 20 RRT 15)

The local Job Centre (JC) might have been seen as an obvious route into work, but several interviewees saw this as stigmatising. No one reported getting a job directly this way, and only Luc found it helpful. Most interviewees who had difficulty in finding employment saw it as a 'last resort', or were too old to use the youth service, Connexions, that had helped James.
I walked in ... enquired about the New Deal, she asked if I had just come out of prison. That was a bit of a shock. I said, ‘No, I’ve got kidney failure and I need help’ ... they think everybody there is trying to cheat the system. (Raj, 22 RRT 16)

I feel a bit embarrassed ... I don’t know why ... just (JC staff) might think ... I’m stupid, ‘cos I can’t get a job, so you’ve got to come here as a last resort. (Kelly, 17 RRT 4)

(JC) said couldn’t put me in a job, ‘cos I didn’t really have any qualifications or experience, so they put me on an IT course ... that helped my independence no end. (Luc, 24 RRT 18)

Unemployable
Three long-term unemployed males were well enough to work, but had few/no qualifications. Oliver and George had never worked, Tristram had worked in the past, but all had lost motivation.

(I did) a year extra course ... when I went on to do what I really wanted the problems started ... it’s taken it’s toll at the worst time. ... I can probably get a job ... like in a shop, but it doesn’t really do much for me ... I’ve often thought (of)... some job with computers, but I don’t know if I’d really want to do that. (George, 29 RRT 18)

You think about a lot, I thought, if I had children when I started dialysis, there is no way that I would have sat back and ... relaxed, I would have gone out there and I would have persevered with work. (Tristram, 29 RRT 5)

Several, with different attributes, continued to study towards an employment-related goal.

I’m on an Access Course ... lined up to go to University ... I’ve wanted to do counselling ... ever since I’ve ... had counselling. (Kieren, 29 RRT 7)

Summary
Many interviewees experienced constrained choices as they entered the employment market, compared with similarly qualified peers. Some constraints were directly related to their health, including RRT modality, and/or to their educational attainment. Interviewees who were not well enough to work full time were constrained by the social structure of the workplace and institutional attitudes which saw fulltime work as the preeminent model of employment. Those with low levels of educational achievement who were on dialysis appeared to be most constrained, and most were not working. With better health and higher levels of educational achievement, most found some kind of employment, or continued to study.

However, whilst several relatively well postpubertal onset interviewees found it necessary to give up previous employment ambitions and established plans, relatively well prepubertal onset interviewees appeared to have adjusted their
expectations downwards over their many years of chronic illness experience. Thus, many of the interviewees who were employed, whether they were in full time work, part time work, insecure short term employment or were self employed, considered themselves 'underemployed' in the sense that they were not using their qualifications and abilities at the level they would have done had they not been ill.

Prepubertal onset interviewees were significantly more likely not to be in paid employment, and those who were ill in very early childhood were most numerous among those not in paid work.

7.3.4. Stigma and disclosure

Being discreditable

Most interviewees seeking employment were concerned about discrimination and rejection and chose to present themselves as 'normal' to potential employers. Stories about the difficulties other ERF patients had encountered were well known, and many older interviewees, irrespective of age of first presentation of ERF, and irrespective of previous experience of stigmatisation, said disclosing their health status to a potential employer was problematic.

'You get better, now what? ... applying for conventional jobs, my CV's clearly like a minefield ... you can make it look as good as you can, but I'm not going to lie on it ... it wasn't easy. (Henry, 30 RRT 19)

Interviewees talked about feeling vulnerable to discrimination in two main ways: firstly, potential employers' reactions if they disclosed relevant health information at all, and secondly, the negative assumptions employers might make about gaps in their employment history, poor GCSE results, unfinished college courses, and/or late achievement of educational milestones.

I don't like telling employers ... When they say on the application form, have you had any operations ... illness, I just put 'no'. I do lie ... (because they might think) 'She's had a kidney transplant ... we don't want her here'. (Debra, 27 RRT 4)

I've put in loads of applications ... it doesn't seem to have made any difference, whether I disclose it or don't ... The issue (is) with my grades ... I don't wanna disclose my GCSEs, they won't understand, unless I explain. (Amy, 24 RRT 7)

Discrediting employment experiences

The problematic social representation ERF and the superficiality of public knowledge has already been discussed, but its impact is illustrated by two contrasting employment experiences: Luc who 'encountered' an employer familiar with ERF, was
judged on the basis of her limited knowledge, and dismissed after a few months in his first job; Mario, a long-standing employee, whose employer had lived with someone with ERF, was supported.

*I were quite lethargic ... tired, my boss wasn't particularly sympathetic, she said, 'My friend's on dialysis and she's fine' ... Then I had to go into hospital ... when I went back ... they'd trained somebody else to do my job.* (Luc, 24 RRT 18)

*I got a blurry bit in one of my eyes ... and headache. That was how work found out (PD)... they were very good, the senior partner, he'd lived with someone ... on haemo ... they'd got to know me.* (Mario, 28 RRT 15)

Some public sector employers and large retail organisations, with well-developed equal opportunities policies, had provided supportive environments.

*If you're having a lot of other related health problems then you're probably not able to get a job that fits in around that. I mean the Civil Service is great for that ... one of the best employers to work for. You can take time off for anything like that, and they won't bat an eyelid.* (Sara, 27 RRT 2).

*They're so good here ... they employed me ... when I was on dialysis ... then when I had the transplant ... they employed me ... for a job full-time.* (Millie, 26 RRT 16)

*I'd done at least a year full-time... then I was off for about 15 months ... but their reaction ... buy me a mobile phone so I could come out and not worry about missing the transplant call ... I've always enjoyed work, they've always been a good employer.* (Daniel, 27 RRT 10).

However, large organisations could not be relied upon for support, and Marc working in a large IT company was made redundant when a car accident precipitated depression, and he felt unable to drive to work. The depression was seen by his psychologists as related to his disrupted childhood and family breakdown. Satish, whose short term contract had not been renewed, felt he had been discriminated against.

*I tried to work from home ... they said that they weren't satisfied with me working from home ... (eventually said) 'We'll have to let you go then'.* (Marc, 30 RRT 10).

*I may have over done (permitted sick days) ... but where I felt ... different ... (was) everyone (with) like a cold or a cough ... they managed to get away with that.* (Satish, 28 RRT 2)

Overall, some of the interviewees who became ill again, or began RRT, after they started work, felt they were discriminated against, but others enjoyed good support from their employer. Those who were supported had all been all well established at work before they became ill (again).
Disclosure as a critical moment
The balance between choosing to hide their illness and choosing to disclose to a potential employer was a fine one. Disclosure was potentially a critical moment for interviewees; one likely to determine whether they were offered employment or not.

Many interviewees as illustrated above had found employment that avoided disclosure, whether in temporary work or by becoming self-employed. Some seeking permanent employment decided to be truthful about their health, and then the timing of disclosure became clearly important. Samuel described how he tackled this tactically, and disclosed his health status only when he judged the employer had decided that they wanted to employ him. However, Samuel (and perhaps Anna) was exceptional among the interviewees in being confident, academically extremely able, and very focused.

My attitude ... is to demonstrate ... that I am more than capable of doing whatever it is that they want me to do. Once that has been established, probably in the 3rd round of the interviews, I tell them. I delay disclosure ... that is the tactic. (Samuel, 28 RRT 17)

Jon got the timing wrong, and early disclosure to a potential employer, by email, meant his informal job offer was withdrawn.

(He said) ‘Jon you’ve got a great CV ... could you come in for a chat, I’d like to offer you something?’ I emailed him back ... about my renal failure ... he emailed ... ‘I have to reconsider, I don’t think you’ll be able to fit the work in with your hours’. (Jon, 27 RRT 8)

An alternative strategy, for those with high level educational qualifications, was to anticipate future difficulties, and take a pragmatic approach to choice of employment sector. Edward had moved successfully between professional jobs, even changing career several times, but his health had clearly influenced the choices made; he was less well, so had just retrained as a teacher12.

Full disclosure by registering as disabled was presented as a ‘last resort’ strategy for those who could not find work. Most interviewees saw being disabled as stigmatising, and something that did not apply to them, although ten had registered as disabled in order to claim DLA (Appendix 3, Table 5). The Access to Work programmes used by Jon and Henry were for people with disabilities unable to find other employment, and perceived as stigmatising.

12 Edward not working because was highly immunosuppressed. He was being worked up for an incompatible living donor transplant from his father in the school holidays.
A government initiative to get people who are on benefits, long-term, or disabled people I suppose, they class us, to get back into work. (Henry, 30 RRT 19)

Extend Scheme ... it's like a ... kind of people with um ... a disability. I just thought this has got to be a way in for me. (Jon, 27 RRT 8)

Some with previous experience of 'being found out' after presenting as normal, were looking for a second job. They faced choices about whether to disclose their illness or not, and took into consideration their previous experience. Mario was looking for another job after a successful transplant; Luc, having got a transplant after a 3-year wait, sought professional advice when he started to look for work. Both favoured disclosure, supported by a claim they were now 'well' with a transplant.

When I started work I didn't know how to tell them ... now I'm ... thinking (about) ... when to tell people, although telling them you've had a transplant is going to be a lot easier than trying to tell them you're on dialysis. (Mario, 28 RRT 15)

I put it on my CV ... (college) said, 'You can leave it off, but then they can come back ... say, 'You didn't tell us about this'. So I thought it's best to disclose it straight away. (Luc, 24 RRT 18)

Summarising, interviewees' accounts of accessing employment had a recurrent theme of needing a strategy to manage disclosure of their health status to employers, centring on how, how much and when to tell a potential employer. Most interviewees wanted to present themselves as 'normal' to employers and colleagues in the workplace, but worried about being discredited. Thus many who were in paid employment had used non-disclosing routes into employment, such as temporary work, and their work simply stopped when they became ill; or they were self-employed. For those who chose disclosure, the timing of disclosure was a critical moment. A few interviewees told employers in advance, or during the interview process, but not all had managed this successfully. Full disclosure, or registration as 'disabled', offered access to employment via schemes for people with disabilities, as did using the Job Centre, but these were seen as stigmatising and a last resort.

In employment, some had negative experiences of disclosure and felt discriminated against. Being 'found out' at work was another critical moment, where, if the discredited interviewee was already established in the workplace and valued they were supported, if not they lost their job. A few workplaces, whose value systems supported social inclusion, such as the public sector and some large corporate organisations, were seen or perceived to be supportive.
7.3.5. Social identity as employed

Almost all study participants reported it was important to be in paid work, with males finding it significantly more important than females (Appendix 3, Table 36, p=0.03). Most of the older interviewees' said their friends were working or studying, and it appeared to be important for them to present themselves to the interviewer as similarly purposefully occupied. Only Hanna and Petra said that paid work was not very important to them: Petra perhaps because an alternative positive identity was available to her as a wife and mother, and Hanna about to go to university.

Most interviewees expected to be employed, most had experienced one, or both, of their parents working, and in many cases had seen their parent/s' efforts to stay in work when they (the interviewees themselves) had become ill. Only two prepubertal onset interviewees, both in one-parent families (Oliver and Tristram) could be seen as part of a 'benefit culture', but both their mothers were unwell. Otherwise, work was presented as something interviewees felt they needed to do with themselves, or their time, and if they were doing 'nothing', they needed to justify why they were not working.

I worked full-time, but I've had a year off now, 'cos (my son) was born last year, and I would like to go back to work ... when he is 2. But if anything comes up now, obviously I'll take it ... 'cos nowadays it's getting harder and harder to get. (Debra, 27 RRT 4)

I don't know what I'd do if I wasn't able to work really. I had ... 4 months (sick leave) ... after my second transplant ... I just hated ... I'd nothing to do with my days, nothing to do with myself. (Sara, 27 RRT 2)

I'm not doing anything at the minute ... anything at all ... I'm just helping my Mum. (Lyn, 19 RRT 9)

Gender

Male interviewees' attitudes to being unemployed reflected the particular importance they attached to paid employment as part of their gendered identity. Several who were unemployed felt like failures, less than a 'whole 'person'. This did not appear to be the case for the female interviewees.

When people say, 'What do you do?'... you don't wanna (sic) say (waiting for an operation) ... I felt like a failure. (Henry, 30 RRT 19)

I wanna be independent, I wanna be able to live by myself, pay my own rent, run my own car, stuff like that. 'Cos otherwise it ... doesn't make me ... a whole person. (Kieren, 29 RRT 7)
It gets to … where I have to say, ‘I’m not working at the moment, it’s not that I’m a lazy so-and-so … I’m a dialysis patient’… (but) I don’t wanna be doing dialysis, I wanna be working. (Tristram, 29 RRT 5)

Those unemployed also risked being judged for living on benefits, when appearing well enough to work.

He feels that he doesn’t fit in with them, because they all go to work, and go on expensive holidays … I say, ‘Friends like that you don’t need ‘em, but they can be like, ‘Oh you’ve always ponced off the state’. (MTristram, 29 RRT 5)

One interviewee, who was highly qualified, driven and determined, was judgmental of others who did not appear to make the effort, displaying the kind of attitude those unemployed feared.

I’ve had 27 years’ experience of it … It’s down to the individual themselves … there are patients who come to dialysis, who haven’t got a job, whether it’s because they can’t, don’t wanna work, or they can’t get one, or what, or they feel they’re too tired (Jon, 27 RRT 8).

Three described structural disincentives to being in work, the so-called ‘benefits trap’, whereby they would lose their benefits if they worked too many hours or tried working, and couldn’t sustain the job.

Not being lazy … the kind of take money off you … you think, is it really worth it? … there’s not many places that will take you on for 16 hours a week. (Kieren, 29 RRT 7)

(Work?) Unfortunately not, with being on the dialysis and the toll that’s taken on me … until recently … it’s taken it’s toll at the worst time. (George, 29 RRT 18)

He gets this severe disablement which they don’t give anymore. He would lose that … (and) he wouldn’t be able to get the same level of benefits again (MGeorge, 29 RRT 18).

I’m employed, but doing ‘permitted work’ … up to 16 hours a week, so I do piece-work, as and when it suits me, when someone comes and says I need help with this. (Ben, 29 RRT 5)

Overall, social identity as an employed person appeared to be important, particularly for the male interviewees. ‘Purposeful occupation’, as a student or wife/mother, offered an alternative positive identity, for those not in paid work. Being unemployed had a significant effect on male gendered identity.

7.4. SOCIAL CAPITAL AND EMPLOYMENT

This section examines the role of family resources in the interviewees’ transition into employment. In childhood and adolescence, access to capital was shown to be very
important for the interviewees' in mediating the effects of RRT. The role of social
capital is expected to be different for the interviewees in emerging adulthood, but no
less important.

7.4.1. Family social capital

Where interviewees' families remained intact, both parents were available for advice
and support for the interviewees, as they sought work. They had more time than
single parents to encourage the independence that they knew their children would
need to develop. Parents also provided some of the motivation that their
son/daughter lacked after a period of depression, or helped them adjust to the
employment constraints they faced.

We've said to him ... 'Your condition may attack your kidney, you may lose it and you
may be on dialysis, you need to be able to work around dialysis, you need to find a
job that will help you do that'. (MJames, 16 RRT 12.

(Mum's) tried her hardest, now ... it's down to me to know what I need to do ... I
wanna pursue a career in care, but it's getting the qualifications. (Wayne, 20 RRT 15)

My Dad shoved me out a little bit ... it was the right thing, 'cos I'd sort of comfortable
where I was. (Luc, 24 RRT 18)

Where fathers were working, they provided employment role models, and those
interviewees who had little or no contact with their fathers (2F, 2M) had less access
to this kind of support, and lacked immediate role models.

My uncle has been ... the biggest kind of male influence in my life, apart from ... I've
just had numerous role models ... years ago ... the TV shows I watched ... even to
this day, I still look up to them. (Oliver, 26 RRT 7)

He's got nobody ... he can call a friend ... I think a lot of it does ... stem back to the
fact that he's not had enough male input ... Everything has been female ...his sister,
his auntie, his gran, female friends of mine. (MOliver, 26 RRT 7)

7.4.2. Family network capital and cultural capital

Social network capital in the family was drawn on by interviewees for accessing paid
employment. At least ten interviewees were, or had been, employed directly by the
extended family and/or family friends, or they had provided opportunities for them.
Where families were large, middle class and/or worked in professional occupations,
the employment opportunities they were able to provide for their children were
correspondingly greater. It was also advantageous if parents had access to social
networks through their own employment.
My cousin was going out with a guy ... starting up an IT recruitment company... I worked for him for 3 months ... My other cousin ... (her boyfriend) asked me... (then) I worked for him for 3 years. (Henry, 30 RRT 19)

More or less full-time (main family business) ... I haven't got any major commitments, apart from dialysis. My brother's a pharmacist; I work with him, part-time. (Satish, 28 RRT 2)

It's (IT) like the family business, my Dad does it, my auntie, my uncle ... My Dad needed some help ... I went along to help out and they offered me a job. (Jerry, 25 RRT 12)

I started work straight away where my Mum had worked previously... as an office junior ... I went back as a receptionist. (Millie, 26 RRT 16)

The number of interviewees helped directly is hard to quantify. Many more interviewees had the kind of help that came from having family members in a particular job. Their parents assessed, or got advice about, whether a particular employment destination was possible, sensible and compatible with RRT.

Just because ... stepfather ... was a computer engineer and my mum got hold of an old, old computer for me ... with his help I taught myself IT ... took some courses, and planned my way into (international company). (Marc, 30 RRT 10)

There's a place going at that nursery ... my cousin works there, so she was going to ask like her manager ... she said she'd get back to me. (Kelly, 17 RRT 4)

I had a discussion with her old headmaster ... 'I would give her a (teaching) job, any time of the day', he says, 'I think that her personality ... what she's gone through, and where she's got to ... I'm not saying everybody would ... but I'm sure she'll get one somewhere'. (MMarion, 19 RRT 16)

7.4.3. Family financial capital

Many interviewees, especially those ill from early childhood, remained in education to improve their GCSE grades, or because they were studying for a higher degree. Parental financial capital was drawn upon to pay tuition fees, and most families provided accommodation and food, until the interviewees became financially independent. Some interviewees contributed very limited resources of their own by working part time and/or claiming state benefits.

My family has helped with tuition fees and stuff, and I don't have any student debt. (Cecile, 26 RRT 8)

It was only 60 quid (the)... ten week course (working for charities), 'cos I wasn't working then, they gave me a discount ... My parents ... to the point that they were able, supported me financially. (Henry, 30 RRT 19)
He's fortunate to get (an EMA) to help him ... stay in education ... He gets £30 a
week ... if our income goes up, he gets less. But at least they get something ... and
he's learning a trade. (MJames, 16 RRT 12)

However, some parents were anxious to ensure any resources they provided were
actually directed towards studying, and were keen to reinforce the work ethic.

Dad's careful about the money that he gives me ... if I really need it like say for my
education, he's more than happy to give it for that. (Raj, 22 RRT 16)

Older interviewees, in socioeconomically disadvantaged families, without good
GCSEs, found it almost impossible to catch up the education they had missed,
because state funding for 'catch up' education and/or training was available only up
to age 26. Several were in the same position as Oliver, depressed, living on benefits
with insufficient financial resources to access 'purposeful' activity.

I'm thinking of doing something like (OU course). Of course, they expect some kind of
fee towards the actual tuition... on every kind of thing, they expect money ... that
might be a bit difficult. (Oliver, 26 RRT 7)

In summary, the families of many interviewees were able to offer them routes into
employment through their social networks, and/or support further education and part
time employment using their financial resources. These interviewees were thereby
helped towards independence and accumulation of more socio economic resources
for themselves. The resources tended to work synergistically, so that having an intact
family, good social networks, cultural capital, high levels of educational attainment,
and financial resources in the family, all served to support interviewees into
employment. Those who were less fortunate with respect to any, or all, of these
resources, essentially fared correspondingly less well in both entering and sustaining
a job.

Several families of interviewees who were ill from early childhood, were least able to
provide the social capital and resources to support their children into employment
and/or further education or training, especially those where family breakdown had
occurred. Thus, the early onset interviewees whose lower or delayed educational
achievement made it difficult for them to enter employment, and who were older and
ineligible for state financial support, found that they remained under- or unemployed
for longer than most of their peers, and had little hope of independence.

### 7.4.4. Summary transition into employment

Not all interviewees who wanted to work, and were able to work, had found
satisfactory employment. There were critical moments in their transition into
employment, as there had been in transition from one educational phase to another, and obtaining a first job was one such critical moment. Several became ill just as they finished their education or training and found that employment thereafter depended on their health: how well they were on dialysis, how quickly they got a successful transplant. The timing of any disclosure to a future employer, and any actual moment of accidental disclosure, were also critical moments, in the sense that if interviewees mismanaged these, then an opportunity to become employed could be lost. A few who were well qualified, socially skilled and confident chose open disclosure to employers during the process of finding work (application form or interview). Some who had not been able to find a job they wanted identified themselves as 'disabled' or chronically ill, so that they could avail themselves of voluntary or statutory access to work opportunities.

Most interviewees said they wanted to work, but many found barriers to entering the permanent work force and used non-formal routes into employment and/or flexible types of employment, such as temping, short-term contracts and becoming self-employed, as do many young adults in the 21st century. Interviewees' current health and educational attainment when they wanted to enter the labour market made a critical difference. Health uncertainties and/or relatively poor health or educational underachievement meant that almost half the interviewees worked part time and/or were studying. This group contained many who had failed to get good GCSE passes, but also some who had done well academically, but could not work in their chosen field, or were not consistently well enough to work full time. Those in temporary work lacked the benefits associated with being an employee with a permanent contract, such as sick pay and pension; things they perhaps needed more than healthy young adults. However, temporary work had led to more permanent work for one or two.

In employment, especially in workplaces where productivity was important, the embodiment of ERF constrained some interviewees' abilities to be 'productive', and they found that employers were especially intolerant of them taking time off work for ill health. Such cultures were most often present in businesses/organisations that were profit-driven and/or dependent on manual labour, and offered additional structural/institutional barriers to interviewees in poor health seeking work, especially males. In contrast, the public sector was seen to be a good employer.

The embodiment of ERF made crucial differences to what kind of employment interviewees could undertake. The demands of dialysis reduced the time available for work, and all interviewees, irrespective of their subjective feelings of 'wellness'
experienced being more tired than 'normal' young adults. Heavy manual work was not possible. While being employed was important for all interviewees, it was more important for male interviewees. However, proportionally more males were unemployed or considered themselves 'underemployed', some because they were unable to sustain unskilled manual work, or work very long hours. Being out of work challenged the embodied gendered identity of male interviewees.

Social resources, both their own and those of their families played an important role in supporting the interviewees into employment. Interviewees whose families were relatively rich in social resources benefited greatly, and were more successful than interviewees from more socioeconomically disadvantaged families in building on their educational achievements and social skills to gain satisfactory employment.

There were some differences in employment status related to chronological age of onset RRT. Only six of the fifteen interviewees who were working fulltime had begun RRT before they were 12, and only one was in a permanent post. However, all interviewees with post GCSE qualifications appeared to find it easier to get work and had more choice in what they did. It appeared that academic attainment and social resources were both salient in finding work, but those who had been ill from early childhood, had, on the whole, lower levels of educational achievement than those who began RRT after puberty.

Thus the visible and invisible aspects of the embodiment of ERF, the continuing uncertainty of interviewees' health in adulthood, added to the educational and social legacy of childhood ERF, and resulted in underemployment or insecure employment for many. Cumulatively, they placed the greatest limitations on the employment opportunities of socially disadvantaged interviewees with early onset ERF.

7.5. ADULT FRIENDSHIPS

Success in developing adult relationships is another important foundation stone for building a secure positive adult identity. Survey data showed that having close family and friends was very important for almost all study participants (Appendix 3, Table 40, Table 41), and much more important than having a lot of friends. More than half of the interviewees went out with their friends at least weekly (Appendix 3, Table 42), however, female interviewees appeared to attached more importance to social activities and friendships than males (Appendix 3, Table 43).
The physical body in ERF was likely to play a different role in making and sustaining adult peer relationships for the interviewees from that it played in finding and sustaining employment, as most young adults attach great importance to how they are seen and perceived by their peers. Survey data from the interviewees showed that their appearance (looking good and feeling good) were important for almost all interviewees (Appendix 3, Table 28), but that a third (12/38) felt abnormal or different from other people, and almost half (11/25) were upset about their body scars (Appendix 3, Table 44).

7.5.1. Claims of normality

Most interviewees claimed they were living a 'normal life' (282 mentions across all interviewees' accounts). Even those who in an everyday sense were not 'normal', talked about how they did normal things, like everyone else, and for most, their appearance was in the range of adult 'normality'; even if they were unusually pale, sallow and/or short.

*My last transplant (for 17 years) … I lived an absolutely normal … (but) I'd have the occasional hospital appointment and medication.* (Tristram, 29 RRT 5)

*I'm lucky in the sense … I've always outwardly looked … normal, when I've got clothes on anyway.* (Henry, 30 RRT 19)

*You've got to live a normal life, make the best of what you've got.* (Jude, 22 RRT 10)

Claims to normality chimed with dominant medical discourse, which continually emphasises the 'return to normal life' offered by transplantation, and the possibility of normal life on dialysis. This rhetoric tends to idealise transplantation, and fails to capture the reality of many of the interviewees' experiences, whether transplanted or on dialysis, who find living a 'normal' life difficult, often making patients' concerns appear trivial.

*(My nephrologist said) 'We can start dialysis, get you back to work… it'll be a normal life, the only time that will be affected is that you'll be coming to hospital for a few hours for treatment 3 times a week'.* (Tristram, 29 RRT 5)

Many interviewees were aware of time passing and getting older, that their peer group was 'moving on' in life, and that their own chances of living a 'normal' life were reducing. Life on dialysis was regarded by some as 'life on hold', in contrast to the expected more 'normal' life, after transplantation.

*Whether you think life's on hold, you're still getting older… but it's not actually what I feel at the moment … (but) some people would say it's on hold.* (Edward, 30 RRT 7)
(Holiday) I went with the girlfriend ... it was something I'd always wanted to do, and that is another thing that ... you get held back on. (Kieren, 29 RRT 7)

I'm getting on with my life a little bit, we're looking for a house. (Luc, 24 RRT 18)

The evidence here illustrates the inherent ambiguities of most interviewee's claims to be 'normal', and how those on dialysis, especially, felt that to some extent their 'normal' lives were 'on hold', and life could only return to 'normality' when/if they got a transplant.

7.5.2. Constraints to adult friendships

The overall picture of the constraints to participants' and individual interviewee's adult friendships is captured in Appendix 3, Table 44, Table 45, and Table 46. With respect to importance of the age of onset, analysis of survey subset data related to respondents' social lives found few significant associations as numbers were very small, but tended to show that some aspects of social life were more difficult for those with early onset (Table 47, Table 48).

In their interviews, interviewees described losing some friends when they became ill, as existing friends found their illness difficult to understand, then finding it hard, even impossible, to make new friends.

You definitely find out who are your friends (sic) and who aren't ... without a doubt ... I've got a group (6 or 8 people) who I'd call my close friends ... One of those, I know understands and cares a lot more than the others. (Laura, 30 RRT 19)

I don't have huge amounts of close friends ... it was easier to be on your own than to try and make friends and have people let you down. I suppose it depends what sort of person you are ... it's almost like a defence mechanism ... If you get burned once or twice, you tend to pre-empt it, by cutting yourself off at the beginning ... and that can be quite isolating. (Ben, 29 RRT 5)

Having friends, or a partner ... I have missed out on that ... I feel very frustrated as to if, not when, it's ever going to happen to me ... it's affected me socially ... I never have been one for ... making friendships with anyone ... I've never actually got the confidence to do it. (Oliver, 26 RRT 7)

Survey data showed that many other study participants had similar experiences.

I got diagnosed, and everyone, but God and my wife, freaked out and jumped ship, feeling like your dreams are smashed to pieces overnight isn't nice. Up and down like a roller coaster, although more often up. (Survey respondent)

Time constraints

Some of the challenges to 'normality' came from the new social situations interviewees faced after leaving school, as they no longer saw their school friends...
daily, and the time taken up by RRT made it more difficult to socialise. More than a quarter of all interviewees, felt their illness made them short of time for other activities (Appendix 3, Table 44); survey data (all respondents) showed there was a significant difference between dialysis and transplant patients in this respect (Appendix 3, Table 49).

*Even now my mates say, 'Are you coming out, have you got dialysis?' ... I think 'Well you know I've got dialysis, I've had it for the last 6 years, ... it's every week, Monday, Wednesday, Friday, 3 times a week ... You know I have, don't ask that question'. (Jon, 27 RRT 8)*

**Health constraints**

Modality of RRT made a difference, and survey data suggested that interviewees on dialysis went out socially with friends less often than those transplanted, and missed more outings because they were unwell (Appendix 3, Table 50). Evidence from all survey respondents confirmed that those on dialysis went out socially significantly less frequently than those transplanted (Appendix 3, Table 51), and were significantly more likely to miss social outings because they were unwell (Appendix 3, Table 52). They were also more likely to find it harder to keep close friends, and maybe harder to make close friends, than those transplanted (Appendix 3, Table 53).

Around half the interviewees (17/36) reported in the survey that they had felt like seeing friends recently. Although more than half of the interviewees reported feeling well, only a quarter felt energetic, and fourteen reported feeling tired, all or most of the time (Appendix 3, Table 30). Mental/emotional health was important and the impact of early relationship difficulties for some early onset interviewees appeared to contribute to difficulties in adult life.

*I found it very difficult to get on with people my own age ... things I wanted to talk about that nobody seemed interested in talking about ... That psychiatrist ... made me realise, just how much an effect those ... years between 6 and 11 ... really did have on me. (Marc, 30 RRT 10)*

*It would be nice for me to know other mothers as well ... but even now, I don't find it easy to make friends ... I keep myself to myself (at toddler clinic) ... 'Cos of what I've been through... I just wanna keep myself personal. (Debra, 27 RRT 4)*

Participation in team sport remained an issue for male interviewees. Those who could not play, because the risk of fracturing a limb was too high, remained keen supporters, but sorrow about lack of participation remained.

*He used to love playing football. He really does miss that ... because he used to do a lot of football, and a lot of sport. (MTristram, 29 RRT5)*
Thus, for a considerable number of interviewees, especially those on dialysis which was particularly time-consuming, ERF and its legacy offered barriers to social relationships with peers. Irrespective of modality, not all interviewees were feeling well, and not all those who were well, felt energetic: two fifths were tired, and almost half didn't feel like seeing their friends. Some had lost friends when they became ill, others found their friends had little understanding, and some found it hard to make new friends, together suggesting that some were likely to be socially isolated.

7.5.3. Embodiment and stigma in adult social life

Some interviewees continued to feel abnormal or different in adulthood (Appendix 3, Table 46), but new adult relationships needed to develop and increase in intimacy if they were to become close friendships, and this meant disclosing their health status. Visible differences between many of the early onset interviewees and their peers, such as their small height and immature appearance presented similar problems in adult social settings to those experienced in childhood; and everyday social activities potentially involved exposing embodied ‘invisibilities’ of RRT, such as scars, tubes, and/or distorted body shapes. However, a sudden change in appearance as a young adult was as distressing for those with childhood onset who were re-transplanted, as it was for the older onset group, and disclosure/exposure remained an issue.

It’s not totally true that I haven’t made friends, but it has been difficult … I still find it difficult telling people … If I tell I’ve had a renal transplant, they sort of think… ‘Why are you still going to hospital’ … when I say I’m on my 3rd … it is quite … nice, because then they know that’s why I’m small. (Amy, 24 RRT 7)

I don’t go round in my swimming trunks … when I was 30, I did think, ‘Sod it, I’m getting older anyway, I’ve got a bag there and all the rest of it’ … (but) nobody likes being gawped at. (Henry, 30 RRT 19)

One (big scar) is on my tummy … I like to keep myself covered basically, so then no one can ask no questions, and I don’t have to answer. (Debra, 27 RRT 4)

For those at school with CKD, ‘normal’ life had been possible during previous periods of ill health, but the dramatic change in appearance on starting dialysis meant disclosure could not easily be avoided.

As soon as I started dialysis, I thought, ‘Oh it’s not something you can hide anymore’ … you can’t go on to lie about it. (Hanna, 18 RRT 17)

I cut my friends off when I started dialysis … probably for 6 months … I just didn’t want them round me. I cut my girlfriend off as well … I felt … I suppose a bit ashamed really, that I was so decrepit. (Henry, 30 RRT 19)
Other interviewees, who were transplanted in the school holidays, or after they had left school, had more freedom to hide from their peers and avoid discreditation and/or pity, until they looked relatively 'normal' again.

(Transplantation) made me ... huge basically ... I didn't go out for... about 3 months ... then, I still didn't like it, 'cos I felt like everyone was looking at me. (Marian, 19 RRT 16)

I didn't want people to look down on me or anything, or feel sympathy for me I had difficulty telling ... I were a social recluse ... for nearly 3 years. (Luc, 24 RRT 18)

It's been very difficult to get me out in the past, it's only recently that I've ... started really going out. (Ajay, 28 RRT 17)

Two interviewees had new different, more physically obtrusive technologies to manage as adults; Ben's urinary catheter and Henry's permanent external urine collection bag, added new meaning to the embodiment of ERF. Henry's bag was prone to leak, necessitating a rapid exit from any social setting to take remedial action; wherever Ben went, he needed 'bathroom facilities' to change his catheter.

(Catheterisation is) not such a big deal ... it's a bit like CAPD ... 3 times a day, a fairly clean procedure ... a clean surface and somewhere to wash your hands ... it takes 10-15 minutes... so you've got that intrusion on your .... (Ben, 29 RRT5)

If your bag leaks, it leaks on the spot, there's nothing you can do about it, suddenly you're soaking wet down one side ... so (Henry) seems odd to people, in that he'll suddenly say 'I'm off now'. (MHenry, 30 RRT 19)

However, some interviewees presented themselves as self confident and positive as young adults. Not all were well or transplanted, and it appeared that higher education, including the ability to think more objectively, and maybe success in other areas of social life, such as employment, enabled some to feel less ashamed of their bodies.

I still kept myself fit ... but I think the important thing for me was making sure that I ... lived long enough to enjoy my life. Obviously for that I need to be healthy and fit and having operations that leave scars on you ... if those operations do not do anything detrimental to your health, then, for me, that was fine. (Samuel, 28 RRT 17)

I was quite young when I had the operation, the scars healed quite nicely and it's all quite perfect and neat ... If I have to another one, it's going to all mess it up, but ... it doesn't bother me at all. I'm quite proud of them, I guess. (Anna, 28 RRT 12)

Overall, as emerging adults, interviewees were continually facing new social situations, in which people were likely to make assumptions about them, initially based on their appearance. 'Passing for normal' was easy whilst they looked normal, but was threatened by a sudden change in appearance, exposure of their damaged bodies, or discrediting disclosure. Thus, while damage/impairment due to injury or
sport might be socially accepted/acceptable in young people, the interviewees experienced any display of disfigurement and/or chronic ill health as stigmatising and a source of shame. Many chose to hide either the impairment or themselves, both of which constrained normal peer interaction.

**Disclosure to friends**

Sixteen interviewees reported that having ERF made it difficult to talk about themselves (Appendix 3, Table 44, Table 46) and in their accounts, most described how they managed disclosure to friends in ways similar to those they used in employment. Some found it easier to tell people about their illness as they got older at a time of change, such as moving from home to university, or because they had learned from previous experience, and felt more able to manage or pre-empt awkward questions and avoid others' pity. Others told people only when they had no choice.

(At Uni X) ... I made up a lie about why some person was picking me up every now and again to take me somewhere ... (At Uni Y) people were a lot more accepting than I thought they would be ... I told them rather quickly. I was just treated the same. (Raj, 22 RRT 16)

When it first happened ... I wouldn't know what to say to people, now, if I meet someone new, they ... see a scar or something... I'll tell them ... Everyone at college ... just kept asking me and in the end, I thought, I may as well tell them, I'm going to be here for another 1 or 2 years. (Marian, 19 RRT 16)

From when I went to Uni ... I was more eager to tell people, rather than them notice it and go, 'Oh what's that?' (Carmen, 24 RRT 15)

Several self-confident and academically able interviewees turned their health status into an 'advantage'.

I do tend to (tell people) ... I like the fact that I've been lucky, and ... that I'm slightly special because of it. (Anna 28, RRT 12)

When I entered university ... I actually raised the whole example of transplantation as part of my answer to a question ... I've been quite comfortable talking about it from day one, it's a medical condition. (Samuel, 28 RRT 17)

Almost all interviewees appeared wary of disclosing too much, or disclosing too soon. It might have been expected that later onset interviewees would find it easier to talk to other people about RRT, as their friends were around, and old enough to understand, when their kidney failure occurred, but most feared stigma and/or discrimination, some had experienced it.
Non-disclosure
Many interviewees, especially early onset interviewees, chose not to talk about their illness at all, except with the few close friends who were around at the time they were ill. If they had lost touch with them, they knew no one who had some memory of their past illness. Some simply lied. The following are interviewees' survey responses.

I do not talk about it and have always made a point just to get on with it. (Marc, 30 RRT 10)

I don't let them know usually. (Lyn, 19 RRT 9)

Don't ever tell (people) I'm a transplant patient. (Tanya, 28 RRT 11)

Several, mainly, but not exclusively, male prepubertal onset interviewees, compartmentalised their illness and kept it 'boxed', separate from their everyday presentation as 'normal'.

When I'm on the dialysis, I'm on dialysis, when I'm off dialysis, I'm a normal person ... I don't dialyse at home, 'cos ... I want to keep the separation between home and dialysis ... You never get away from it ... so it's how you separate it in your mind. (Edward, 30 RRT 7)

Non-disclosure was in many ways easier for interviewees who had reached normal height, looked well and behaved 'normally'. However, any unusual behaviour patterns, or others' careless talk, meant that unplanned and unwanted disclosure was always possible.

I'd put them (tablets) in my pocket, so no one could see ... then I'd start ... sort of take 'em sliding back ... My immediate friends knew obviously ... but outsiders weren't allowed to know. (Millie, 26 RRT 16)

I could see (my sister) talking ... I said, 'You didn't tell them about my illness did you?' ... She went, 'No I didn't', then when the woman come past me, she said, 'God bless you, I've heard all about you when you was younger'. (Millie, 26 RRT 16)

Some with long and complicated histories found non-disclosure harder as they got older, because everyday social life generated apparently trivial questions, like, 'Why don't you want a drink?', which did not have a short answer that could be guaranteed to close down unwanted further questions. However, the negative side of not talking about their health meant that 'normal' friends did not easily understand, and interviewees did not get the support they might have liked.

It's too big to tell, where to begin? (Ben, 29 RRT 5)

I need people to understand that sometimes... I don't want them to see me, when I'm upset, or ... ill or whatever, I want them to see me when I'm OK. (Alice, 24 RRT 9)
Difficulties in self-disclosure remained unresolved for some interviewees who continued to present themselves as normal to new friends, and they lived in constant fear of being found out and discredited. Their social identities were therefore at risk in trivial everyday situations, as there was increasingly more to hide.

7.5.4. Summary of constraints to peer relationships
Most interviewees claimed they lived normal social lives. It was clear that adult peer relationships were important in most interviewees' lives, but for some, especially those on dialysis, their physical health per se, or the demands it made on their time, constrained their ability to share the social lives of their peers. Additionally, for some, the meanings they attributed to their ill health and the experiences they had of others' reactions when they found out about it, formed barriers to making new friends, and for some, keeping old friends.

Some interviewees had experienced rejection by their friends when their friends found out about their health, or feared rejection if they shared more personal information and/or exposed their damaged physical bodies. Many tended to keep themselves and/or their bodies hidden from view, especially if their appearance changed suddenly. Thus, very few interviewees appeared comfortable with disclosure of illness, but those that disclosed were more comfortable with their adult social identities and 'multiple normalities' (Sanderson, Calnan, Morris et al., 2011). Some of the later onset group, especially those very recently ill, found they didn't want to tell anyone at first, but later, felt able to tell people, perhaps because their ERF was more recent, or they were more mature when it occurred, and/or they had not suffered the rejection they feared.

Those who felt unhappy about disclosure employed a range of strategies to completely avoid, then if impossible, to mitigate its impact. They strived to maintain a 'normal' identity, but this restricted the progress of new friendships which normally involves a gradual mutual disclosure of more personal information, feelings about, and future plans for, work, holidays, marriage, and children. Thus, these interviewees suffered from perhaps the very social isolation they feared had they discredited themselves as 'normals'.

7.6. SUMMARY
On entering the adult world, the study participants faced many transitions. All, with few exceptions, moved from paediatric renal care to adult care, and all on leaving
school, moved into training, further/higher education, employment and new social
relationships. The experience of transition into these adult areas of social life, areas
where relatively little was known about childhood onset ERF, was captured in the
open responses to survey questions and much more fully in the interview data.

7.6.1. Independence, choice and agency
Interviewees' abilities to increase agency over their own lives and make their own
choices about their adult lives were constrained by the legacy of childhood illness.
Continuing health uncertainties in emerging adulthood affected their ability to assume
and assert their independence in ways normally expected of young adults, that is, to
make their own decisions, get a job, and make successful new relationships.

For the early onset group especially, the interviewees' agency had also been
constrained by powerful others (parents, doctors, nurses) telling them what to do,
how to behave and how to manage their lives, for many years. In adolescence they
had been encouraged to assume responsibilities for treating themselves and
adopting a healthy lifestyle, in anticipation of transition into adult care and adult life.
However, for all the interviewees, scope for assuming more and different health
responsibilities was limited: they had choice only over whether they
followed/complied with medical advice. Some chose to ignore advice in areas they
felt competent, but any failure to follow medical advice had potentially serious
consequences, for their health, and their lives. Some found looking after themselves
a heavy responsibility, both in the everyday sense of managing their medication and
managing the practicalities of daily health care. All relied on their families, and to a
lesser extent, their friends, for emotional support.

7.6.2. Life course transitions
Transition from paediatric care into the adult hospital world was a transition into a
familiar, but different world. The overall culture of renal medicine was familiar, but
adult units proved less supportive and more frightening places to be. Interviewees
were expected to be almost completely independent of their parents and make their
own health decisions, albeit limited in scope.

The adult world of employment was different from the hospital environment, and
successful transition demanded adult levels of independence, and a reasonably
secure social identity. Some interviewees experienced discrimination in seeking
employment, some, rejection and dismissal when they became ill at work. Most had
to reduce, or had already reduced (for many early onset interviewees), their
expectations as to what kind of employment they would obtain. Both physical and emotional health were needed to sustain employment, and many, especially those on dialysis, found it difficult to obtain paid work. Emotional health problems meant some interviewees felt unable to enter a competitive job market, and one who became mentally ill whilst working, felt he had been unfairly treated when he was dismissed.

Transition into employment presented several critical moments when adverse health events had a disproportionate impact on some interviewees' future opportunities. Being seriously ill just as they left school and/or started work, or shortly afterwards, was one such moment, as newly employed interviewees had had little time to establish themselves as valued employees. Applying for a job or being interviewed for work presented another critical moment, as many faced a dilemma about the timing of disclosure of their health status, and considered how to manage interviewers' preconceived ideas of how ERF might affect their work. An employment interview was a critical moment, as health questions raised at interview were likely to require a split second decision about how to answer, and needed to be anticipated, so that they could be managed.

In seeking employment, interviewees used a range of strategies to obtain paid work without disclosing their health status, including a variety of non-competitive strategies, such as short term contract work or self employment. Prevalent societal attitudes to disability meant that identifying themselves as disabled in order to obtain supported employment was rejected by most interviewees as stigmatising; however, two eventually gained employment via schemes for people with disabilities. Similarly Job Centres were seen as stigmatising. Several interviewees found it impossible to gain (re) employment, and were unemployed.

For most of those in work, colleagues knew nothing about ERF as a disease affecting young adults, and none had prior knowledge of the interviewees' health/health history. Thus, any sudden and unexpected deviation from 'normal' behaviour, such as those occasioned by a need for a change of RRT, an inexplicable absence from work, and so on, needed to be anticipated, explained, and managed. Most interviewees feared discrimination and chose to pass for normal, hiding their illness from colleagues and employers.

Most of the employed interviewees had working transplants, but the physical embodiment of ERF was important because it limited the work they were able to undertake. Some interviewees were unable to meet the expectations of working full
time and for long hours in manual jobs, or were underqualified for office-based work, which limited their employment opportunities. Tiredness, fitness and stamina were particular issues for those whose employment choices were already limited by poor academic performance at GCSE, particularly male interviewees. Some interviewees had given up physically demanding jobs for less demanding work, or given up jobs undertaken when they were well, when they found deteriorating health made them unsustainable.

Many interviewees relied on social resources in their families as well as their own resources, to gain employment. High levels of social capital in their birth families were particularly important for all of those who were under qualified, had previously experienced discrimination, and/or those who perceived themselves to be unemployable on the open market. In ‘intact’ families, both parents provided gendered role models, and often both were providers of direct or indirect resources to support their children’s entry into the workplace. However, there were many fewer intact families in the prepubertal onset group, so these resources were not as readily available to this group. Where there were more financial resources, interviewees were able to stay in education and become better qualified for the workplace; where there was more social network capital, interviewees had more opportunities to obtain paid work through friends, and friends of the family.

Overall health, social and structural obstacles to employment compounded each other, so that it was interviewees who were seriously ill before puberty, and had experienced one or more of the following, who struggled most to find employment:

- illness at several critical moments,
- working class family background,
- growing up in single parent family,
- lack of success at GCSE,
- were on dialysis.

This picture appeared to hold true, with few exceptions, almost irrespective of how well individual interviewees were when they were interviewed. A few interviewees matched most of these criteria, and they no longer struggled to find employment, instead they were resigned to living at the margins of adult social life.

7.6.3. Adult social identities

Most of the interviewees appeared to have entered the adult world uncomfortable with an illness identity, and chosen instead to ‘pass for normal’. The largely invisible nature of ERF, in everyday social life, made this a realistic choice. However, the huge
uncertainties associated with ERF, inherent in RRT, meant they risked being found out, and thereby discredited, by sudden illness or accidental disclosure. Reversals in their health, especially changes to RRT, needed more careful management in adult peer relationships, than they had needed at school, where their peers already knew about their health.

The physical body in ERF continued to be salient in making new friends and progressing in intimacy with friends. Adult relationships brought potentially more and different kinds of disclosure/exposure of their bodies to people who had not known them as children. Social situations, such as leaving home for college life or going on holiday, necessitated choices about whether to continue to pass for normal, or to talk to new friends about what their illness meant. This, many were reluctant to do, but getting older and being in a situation where they had no choice, meant that some interviewees did talk about their illness; others continued to hide it and pass for normal, but found they became more isolated.

Gender made a difference, mainly in that female interviewees attached more importance to every day social life, and participated more often in social activities with friends, than males. Unemployment compromised the gendered masculinity of males, especially those who had no alternative basis for a secure positive adult identity.

### 7.6.4. Summary

The chronological age of the interviewees, the age at which they first became ill, the timing of any new disruption to their life course and the embodiment of ERF, as well as the impact of the stigma of chronic illness on employment or peer relationships, all affected their ability to develop a secure positive adult identity in emerging adulthood. New themes in adulthood were pressures to become independent of their family, and challenges to their developing adult identities resulting from the inadequate social representation of ERF, and associated lack of knowledge and understanding of RRT in the wider social world of employment and friends. The extent to which each, or any of these, things made a difference to interviewees' lived experience of emerging adulthood was also influenced by the individual and family social resources they were able to draw upon.
8. INDEPENDENT LIVING AND INTIMATE RELATIONSHIPS

8.1. INTRODUCTION

This chapter examines the experiences of interviewees living with ERF as they established, or endeavoured to establish, their own accommodation, alone, with friends or with an intimate partner. Their health, the embodiment of ERF, and the uncertainties of the physical body might be expected to have increased salience in intimate partnerships, and the kind of strategies and skills used to manage disclosure in new situations will be explored.

8.2. LIVING INDEPENDENTLY

Living independently is a goal for most young adults, but is being achieved later now than it was 50 years ago. For many, opportunities to leave home, other than for further study, arise naturally from employment, accumulation of sufficient financial resources, and an established network of friends. However, evidence so far presented has shown that many of the interviewees found it difficult to find permanent relatively secure employment, many were on low incomes, and some faced difficulties in their adult peer relationships.

(I know) 5 or 6 people who are all in similarish situations to me ... they've all had problems and questions about achieving independence ... I can't see a way that I could move out of the house without my parents throwing me out at the moment, unless I get a well-paid job. (Ben, 29 RRT 5)

8.2.1. Living arrangements

Fifteen interviewees (8M, 7F) were living independently, 12 of whom were over 25 and half were graduates; almost all came from middle class families (Table 8.1, Appendix 3, Table 56). Thirty two interviewees were 24 or older, and some of the older interviewees who lived at home felt peer pressure to leave, but were reluctant to do so because of the loss of support. Most of those living independently were over 26, and most were transplanted. Six were buying property; others were in private rented accommodation or in social housing.

8.2.2. Gender differences

Similar proportions of male and female interviewees lived independently, but had very different living arrangements. Six men lived alone: all were over 25, five had been ill
from early childhood and two were on dialysis, which in itself brought greater acute health risks and more worries than successful transplantation. Two men with partners lived independently, and two more were engaged to be married but lived at home. No women were living alone: seven had left home (including Carmen), five lived with a partner, and two with friend/s (see table 8.1).

Table 8.1 Interviewees' living arrangements by name and chronological age

<table>
<thead>
<tr>
<th>Age</th>
<th>Living with parent (25)</th>
<th>Living with friends (2)</th>
<th>Living with partner and/or married (7)</th>
<th>Living alone (6)</th>
</tr>
</thead>
<tbody>
<tr>
<td>31.12.06 (N)</td>
<td>(2M, 4F) aHanna, James, dKelly, dLyn, Marian, Wayne</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16-20 (6)</td>
<td>(2)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16-20 (6)</td>
<td>(2)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21-25 (9)</td>
<td>(5M, 1F) aAlice, dGus, dJude, Luc, Matt, Raj,</td>
<td>(1M, 2F) aAmy, aJerry, aCarmen</td>
<td></td>
<td></td>
</tr>
<tr>
<td>26-30 (25)</td>
<td>(9M, 4F) aAjay, Ben, Cecile, aDebra, Eugene, George, Laura, dLuther, aMario, Oliver, Sara, dSatish, dTristram</td>
<td>(2F) Anna,</td>
<td>(1M, 3F) aDaniel, mPetra, Lucy,</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(6M) aDaniel, mSatish, mTanya,</td>
<td></td>
</tr>
</tbody>
</table>

Key:
a = Affianced; Carmen married just after her interview (mother's data)
c = Three interviewees had children, Debra (1F), Petra (1F), and Marc (2M).
d = Twelve were on dialysis; of those 9 were over 20 years (Alice, Edward, Gus, Jon, Jude, Luther, Samuel, Satish and Tristram).
m = Six (Anna, Carmen, Edward, Jon, Petra, and Samuel) were buying properties on mortgage.

More female interviewees than male interviewees wanted to live near their birth families.

_I don't wanna leave my Mum and Dad ... (I'll be)10 minutes if that ... but it's me now, this is my life ... I'm going to live, as opposed to just being. (Carmen, 24 RRT 15)_

_Until I actually meet somebody special and go and live with them, I'll just stay where I am ... I'm so close to (my parents) and they're so supportive ... I think I'm quite paranoid (about the risks) when they're not there and I'm on my own. (Laura, 30 RRT 19)_

Three men described how their health had disrupted previously settled independent living arrangements: Marc had separated from his partner after he became mentally ill, Daniel was forced to return from overseas, and Henry forced to leave a flat he shared.
I shared a flat with a friend, then I became violently sick ... (Now) I live just down the road from my Mum. (Henry, 30 RRT 19)

One night I said, 'You're not well, you need to stay here', he said, 'No I'm a grown man, I'm going back to my own house' ... In the morning he couldn't see, couldn't walk, couldn't hear, couldn't move his head, he was dizzy ... I went down there. (MHenry, 30 RRT 17)

For the men, living alone appeared to be a constrained choice, arrived at variously because of their age and peer pressure, because their workplace was distant from the parental home, because they were unable to find someone to live with, or because a previous relationship had broken down. None said their parents had instigated their move out of the family home, most simply wanted their independence.

Social class and cultural background appeared to make a difference as to whether interviewees remained living at home as they got older. More of the older male interviewees who remained at home content to be looked after were working class. It is possible that the middle class interviewees had more financial resources, and for them either the stigma of remaining at home became too great as they got older, or the demands of their professional job required a move. Men whose cultural background was Asian, appeared more content to adhere to cultural norms and remain at home.

8.2.3. Financial resources

All the interviewees, except two, said that having sufficient money to be financially independent was important (Appendix 3, Table 41). Several were clearly earning enough to support themselves in independent accommodation: three earned more than £2000 monthly, and two, earned between £1500 and £2000; all of these, except Ajay, lived independently of their parents, as did five of those earning between £1000 and £1500 (Appendix 3, Table 57). Two female interviewees were supported financially by their male partners (Amy and Petra).

Several interviewees were ambitious, but almost all of the older interviewees were realistic about their earning potential. Most saw both education and employment as necessary for leaving home and becoming independent, but worried about whether they could sustain employment, earn enough for their own needs and/or enough to achieve 'normal' adult goals. Several interviewees felt that lives were not progressing because they could not sustain a job, get any job, or a good enough job, to move out of the parental home.
I would like to get a place with my girlfriend, but simply can't afford to ... I try to get a better job and am turned down ... I can only see being stuck at home. (Matthew, 24 RRT 14)

We need money to do anything ... (plans for living abroad) are off the cards, 'cos we haven't got any, that's what we're trying to address at the moment. (Daniel, 27 RRT 10)

When I get my master's, I want to get a job ... if I don't have enough money, I won't be able to (buy) my franchise. (Alice, 24 RRT 9)

The level of earned income might have been expected to largely determine whether the interviewees were able to live independently of their parents. However, several with no earned income, or very little, were able to live independently and were resourced in different ways. Some had an employed partner, some had high levels of unearned income from benefits and/or rental income, and some were supported financially by their family.

I've been in here just over a year ... (my parents) helped me out with this as well, 'cos they know how much I wanted to get my own place and it would help me to be more independent. (Jon, 27 RRT 8)

I was left money ... from grandparents ... and that's basically my house fund (Jude, 22 RRT 10).

I put my name down on the council list (aged 22), when I was 25 they offered me a flat... me and (boyfriend) were together, and we just thought we'll make a go of it see what happens (Millie, 26 RRT 16).

It was 'common knowledge' amongst ERF patients that obtaining a mortgage was problematic, because of the need to disclose health status. However, only Lucy amongst the small number who had their own mortgages mentioned that health had been an obstacle, and for her the cost of mortgage protection insurance had been prohibitive.

I've had no trouble getting a mortgage, but I think the way things have gone, that they really will, you know, lend money to a dead man. (Henry, 30 RRT 19)

We got quotes of about £30 a month, they said it depended on writing to doctors, and then mine came in at £150 a month. (Lucy, 27 RRT 9)

Henry's health was too uncertain to sustain permanent employment. When interviewed, he was working part time and engaged in entrepreneurial activities with a friend, aiming to save money for himself and to relieve the load on his mother.

The reason I'm doing it (buy to let) ... is so I can relieve some financial pressures from my Mum ... I know there will be a time when I won't be able to work again. (Henry, 30 RRT 19)
8.2.4. Summary living arrangements

Access to sufficient family and social resources was necessary for interviewees to live independently of their parents. Gender made a difference, in that more men living independently, lived alone, but women living independently lived with a partner or friend. More women talked about wanting to remain close to their families. The need to remain living near their parents for social and/or psychological support was obvious for some, because of the inherent instability of their health, and the risk of sudden death on dialysis. However, cultural expectations were such that it could be stigmatising for the interviewees to be living at home in their late twenties, and this was likely to become more pronounced if they remained single into their thirties.

8.3. TRANSITION INTO INTIMATE PARTNERSHIPS

Some interviewees had made successful transitions into employment and independent living, others had not, but individual experiences were very varied. The stigma of unemployment, and of remaining at home with their parents, meant that some interviewees, those with few friends and those in poor health (especially males) had experienced more difficulties in securing positive identities as young adults, and were thus likely to face even greater challenges in seeking intimate partners.

8.3.1. Important methodological issues

Interview questions related to intimate partnerships were clearly sensitive. Few interviewees spoke openly about their difficulties in finding an intimate partner, but such difficulties were implicit in many of their accounts, or conspicuous by their absence. Interviewees who were interviewed by telephone appeared to speak more openly about intimate issues than those who were interviewed face to face, and a distinction is drawn in this section, where relevant, between the face to face interviews (F2F) and the telephone interviews (T).

Several mothers spoke freely about the relationship challenges they saw facing the interviewees, and described things that interviewees themselves probably found too shameful and painful to disclose themselves, face to face or on the telephone.

*He's struggling at the moment ... all his friends have got girlfriends, (but) he isn't at an age where the girls see him for himself, they're still after the good looking lads.*

*(MJude, 22 RRT 10, T)*

*Finding people who share his difficulties, is something I've thought about, suggested, and talked to him about over the years, in terms of partners for him ... not necessarily*
partners, but sharing difficulties with people who would understand, and he'd be able to disclose to, but he doesn't want to do that. (MHenry, 30 RRT 19, F2F)

He's had girlfriends ... he always says, 'I don't want to find a nice girl ... they fall in love with me and maybe we have children, then I'm gonna die and leave them, it's not fair'. (MTristram, 29 RRT 5, F2F)

He did have a girlfriend once, but she quietly disappeared. (MGeorge, 29 RRT 18)

(He said to the counsellor) ... I absolutely hate, even getting in the shower, to see all my scars on my body ... girl friends, of course I want a girl friend like anybody else, but I hate the thought of what she'd think of my scarred body. (MOliver, 26 RRT 7)

These data illustrate what interviewees' mothers 'knew' and felt about their children's feelings and experiences of trying to find an intimate partner. Some mothers were frustrated by their own impotence, because they had become powerless to help the interviewees as they got older, especially in finding a partner. They saw them losing the 'normality' they had strived so hard to achieve, and watched their single status becoming more problematic, as they fell further behind their peer group in reaching adulthood. Their perspective was very important here.

8.3.2. Overview of partnership arrangements

Three quarters of interviewees thought that having an intimate partner was important (Appendix 3, Table 41). Eleven, all 24 or older, were, or had been, in established intimate partnerships, including those engaged to be married or living together, and two were single parents. All had met their partners when they were relatively healthy, and living with a transplant, and seven had become ill before puberty. Five more interviewees mentioned being in non-cohabiting relationships, two aged under 21 (Table 8.2 below). Others, not in intimate relationships, described previous experiences of them in interview data.

It is likely that living at home might act as a deterrent to establishing an intimate partnership, as it offers little privacy for relationships to develop.

I have a very good friend... my Mum thinks she's my girlfriend, so, if I'm actually going out with (my real girlfriend), I'll say it's my friend that I'm actually going to see, just to keep her off my back. (Ajay, 28 RRT 17)
Table 8.2 Interviewees’ intimate partner relationships by name and age RRT

<table>
<thead>
<tr>
<th>Name</th>
<th>Age 2006</th>
<th>Age RRT</th>
<th>Nature of relationships incl. previous where applicable</th>
<th>Modality at time of partnership</th>
<th>How they met, if known</th>
</tr>
</thead>
<tbody>
<tr>
<td>Debra</td>
<td>27</td>
<td>4</td>
<td>Single mother with custody (separated)</td>
<td>Transplanted and stable</td>
<td>n/a</td>
</tr>
<tr>
<td>Amy</td>
<td>24</td>
<td>7</td>
<td>Co-habiting</td>
<td>Transplanted and stable</td>
<td>Blind date</td>
</tr>
<tr>
<td>Lucy</td>
<td>27</td>
<td>9</td>
<td>Co-habiting</td>
<td>Transplanted and stable</td>
<td>Local pub</td>
</tr>
<tr>
<td>Petra</td>
<td>30</td>
<td>9</td>
<td>Married with teenage child</td>
<td>Transplanted and stable</td>
<td>At school together</td>
</tr>
<tr>
<td>Marc</td>
<td>30</td>
<td>10</td>
<td>Single father without custody (separated)</td>
<td>Transplanted and stable</td>
<td>Amateur dramatic society (aged 19)</td>
</tr>
<tr>
<td>Daniel</td>
<td>27</td>
<td>10</td>
<td>Married</td>
<td>Transplanted, but function deteriorating</td>
<td>Working abroad</td>
</tr>
<tr>
<td>Jerry</td>
<td>25</td>
<td>12</td>
<td>Co-habiting</td>
<td>Transplanted and stable</td>
<td>Internet Dating line</td>
</tr>
<tr>
<td>Carmen</td>
<td>24</td>
<td>15</td>
<td>Married (post interview)</td>
<td>Transplanted and stable</td>
<td>Cousin’s friend</td>
</tr>
<tr>
<td>Mario</td>
<td>28</td>
<td>15</td>
<td>Engaged, waiting for fiancée to join him from abroad</td>
<td>Transplanted and stable</td>
<td>Internet Pen friend special interest</td>
</tr>
<tr>
<td>Millie</td>
<td>26</td>
<td>16+</td>
<td>Co-habiting</td>
<td>Transplanted, but function poor</td>
<td>Brother of sister’s boyfriend</td>
</tr>
<tr>
<td>Luc</td>
<td>24</td>
<td>18</td>
<td>Co-habiting temporarily in his parents’ home</td>
<td>Not known</td>
<td>Internet Chat line</td>
</tr>
</tbody>
</table>

Not cohabiting or mutual commitment less permanent

| Samuel  | 28       | 17      | Stable non-cohabiting girlfriend                      | Dialysis                        | n/a                                    |
| Eugene  | 27       | 9       | Stable non-cohabiting girlfriend                      | Transplanted and stable         | Workplace                              |
| Wayne   | 20       | 15      | Stable non-cohabiting girlfriend                      | Transplanted and stable         | n/a                                    |
| Matt    | 24       | 14      | Stable non-cohabiting girlfriend                      | Transplanted and stable         | n/a                                    |
| Marian  | 19       | 16      | Stable non-cohabiting boyfriend                       | Transplanted and stable         | n/a                                    |

(Survey Qs 1d, 1e, 5d and interview data)
It is hard to comment on whether the proportion in partnerships is lower than might be expected because of the different ways that national statistics are collected. However, the effect of factors already discussed on their peer relationships, especially issues concerned with identity and, crucially, the embodiment of ERF, would be expected to affect their success in sharing intimate sexual relationships with a partner.

8.3.3. Stigma and disclosure

Sense of self
Many prepubertal interviewees without a partner appeared to lack self confidence in seeking one, and to have had little previous experience in negotiating intimate relationships. Oliver, below, was an extreme case:

My relatives are either very patronising ... 'There's someone for everyone, the right person will come along'... or over the top, 'OK well ... it's not going to happen if you don't put in the effort'... it makes me think, 'Why are you telling me that ... when I don't know how?'. (Oliver, 26 RRT 7, F2F)

I would like to know that he could socialise ... I worry that he won't get a girlfriend ... ... someone perhaps to meet and be with, even if he doesn't want to marry. (MOliver, 26 RRT 7, F2F)

Those who were not used to talking about their illness did not appear to have an appropriate story ready, or have constructed a 'socially acceptable' biography, to explain themselves to potential partners, which might have helped them to manage disclosure appropriately, and protect themselves from rejection. Feeling good about their appearance/themselves was important, and several early onset interviewees talked of not liking themselves enough, and how their self confidence had been eroded by feeling different from other people.

How do you tell you've got this whole history, another part of your life ... I haven't quite worked out ... I haven't had any long-term relationships ... that's quite a big issue (at my age) ... I've tried to increase my sort of circle of contacts with people... so I get used to dealing with more situations, things like that. A lot of it's to do with confidence... and self esteem, which I don't always feel great about, to be honest. So it's about feeling comfortable about myself, before I can take those steps. (Ben, 29 RRT 5, F2F).

I had a few fling periods (at Uni), but nothing came of it, I think that's because I didn't trust the guys ... I didn't ... like myself enough to really believe them ... (guys) didn't know, they didn't ask. It was good in a way, it made me feel like I wasn't a total outsider ... but it still didn't really address ... my self esteem. (Sara, 27 RRT 2, F2F)

I've got massive issues ... I just haven't had a proper relationship in any shape or form. I don't seem to get past about 2 months ... in the past 6 years, there's only
been 2 guys that I’ve really been out with ... (and) we didn’t really talk about it. ... I see ...my future as... having kids, getting married and stuff. But the path towards that is completely foggy, I’ve got no idea how to do it really. (Tanya, 28 RRT 11, F2F)

Lack of self esteem applied to both genders, and some of this was related to relative sexual immaturity, and looking different, as well as feeling different. Amy had very small breasts.

Psychologically I didn’t feel I could go out with a guy ... I still feel ... as if I’m missing something ... If I had the option ... I’d buy a breast implant ... I’m not the sort of person ... that feels confident unless ... it’s all there, so ... it probably did have large impact on me. (Amy, 24 RRT 7, T)

One or two of the later onset group were confident and successful adults, but many also lost self social confidence when they were first ill. Some ‘recovered’ when their appearance returned to ‘normal’, if they got positive identity reinforcement, in education or employment, but more especially success in intimate relationships.

I probably wasn’t (confident) up until I met my fiancé, he made me a lot more confident than ... I ever was before ... I wouldn’t say I was embarrassed, but ... aware that I had scars where other people didn’t ... I would just never wear maybe too short a top ... because it might show my scar. (Carmen, 24 RRT 15, T)

'Underemployment' or unemployment was an issue for many interviewees, but only male interviewees mentioned the difficulties that being unemployed (and on dialysis) presented in terms of finding a partner. The threat unemployment represented to their gendered identity made it a source of shame which needed to be managed at the beginning of any relationship with a potential (female) partner.

It’s very difficult and embarrassing ... if I meet a girl and they start talking to me, 'What do you do?' I wanna be telling 'em, 'Well I’m a successful whatever', but ... I have to say, 'Well, I’m not working at the moment' ... but I don’t wanna be doing dialysis, I wanna be working... looking at this woman ... you could be my future wife. (Tristram, 29 RRT 5, F2F)

Lack of self confidence, and the stigma of being ill, presented serious difficulties for some interviewees in finding a partner, especially the prepubertal onset group, as it had in peer relationships. It also appeared to be important to feel 'good enough', possibly via positive achievement in other parts of their lives. However, finding a partner contributed to developing a positive sense of self.

Disclosure to intimate partners
Few prepubertal interviewees appeared to have had intimate relationships in adolescence. After school, several had been rejected by partners, or potential partners, on account of their illness, especially those on dialysis. There was a
pervasive feeling amongst those on dialysis, that dialysis was a romantic 'turn off',
and that things would only get better when/if they got a successful transplant.

That was the other difficulty in life... finding yourself a girlfriend ... it just wasn't really
happening. I found one when I left school ... she stayed with me 'til I was on dialysis
and then couldn't put up with it much longer. (Kieren, 29 RRT 7, F2F)

I've never really been successful in anything like that, I had one girlfriend at Uni ...
but I had a working transplant then, so that was a bit different ... (now) ... you start
chatting in a bar ... you get on really well, and you say, 'Oh I've got ... renal failure', it
scares them off. (Jon, 27 RRT 8, T)

Even with a transplant, it was not always enough to appear 'normal' and 'look good'.
If interviewees were not as fit, or did not have as much energy, as their friends, they
did not meet partners' expectations of their energy levels.

Guys ... think it's ... your own fault ... you're not fit, you don't look after yourself
properly, you don't eat the right things. They blame it on that, rather than on what's
wrong with you. I've had that quite a lot. (Laura, 30 RRT 19, F2F)

Jude (infertile) told his girlfriend about dialysis, only when it became impossible to
avoid disclosure, and then by telephone. His girlfriend was not 'fine with it', and
quickly rejected him. His own account minimised the significance of this relationship
and the pain the breakdown caused. His mother talked emotively, and at length,
about what it had meant for him, offering possibly a more credible account of the
meaning of rejection for him.

I've recently split up from someone, well it was one of those on, off things .... it was
more because I was messed about a bit ... It was the first time I had to tell someone ...
and it was nerve wracking .... She'd be calling me, 'I'm down the pub, come and
see me .... I had to think, shit (sic), I'll have to tell her ... be honest, ring her and say,
'I'm not trying to avoid you, but I'm on dialysis ... this is why I can't see you tonight'.
She said she was absolutely fine with it. (Jude, 22 RRT 10, T)

This girl friend problem is a real problem ... he went out for a proper date ... I think he
told her quite a lot .... (then) she wouldn't see him again. I thought, 'Oh God that's the
worst possible thing you've done, young lady' ... that's about the only time I've heard
him feel sorry for himself. (M Jude, 22 RRT 10, T)

Laura attributed rejection by successive partners, not only to her lack of fitness
(above), but also to her honesty about whether she would be able to have children.
Alice, similarly rejected several times, was demonstrably angry and hurt, and had
decided not to have any more relationships until she was healthier.

I was with somebody when it happened ... he ... just got impatient once I'd had the
transplant ... because I was taking time to recuperate ... My last boyfriend ... I think
he had an issue with the whole, 'Can she have children or not?'... blaming me for it,
and that's quite hard when you're on the receiving end ... It's still a bit of a sore subject. (Laura, 30 RRT 19, F2F)

Guys ... started asking me out ... (but) I just think I was prone to choosing the wrong people ... (angrily) 'So what if you don't like me, it's probably 'cos of who I am, or you just don't know how to understand ... my situation, and if you're either, then I don't need you ... because at the end of the day... I don't need more hassle if you're not going to be able to understand and ... just be there for me'. (Alice, 24 RRT 9, F2F)

Alice's anger was mirrored by that of Amy, who had similarly decided not to have anything to do with boyfriends for a period in late adolescence. She struggled to find the right word, eventually choosing 'aggressive', to convey how her feelings and attitudes towards boyfriends prior to meeting her fiancé (in a blind date after her transplant), had led her to thinking they were simply too much trouble.

I was really quite ... aggressive when it came to boys ... I didn't want to be bothered with them ... I think it was because I knew that I couldn't ... have a normal relationship as it were. Because I had dialysis every night, I couldn't hang out and stay out all night ... When it came to going to college, I thought, 'Well they're just getting in my way, I don't want a boyfriend, they take up too much time and effort'... I was quite aggressive when we (fiancé) first got together. (Amy, 24 RRT 7)

Gender made a difference to how the interviewees dealt with the legacy of their childhood illness in meeting potential partners. More male interviewees chose a rhetorical style or impersonal language to distance themselves from the painful experiences they were describing, and appeared more comfortable with matter-of-fact descriptions of events. The female interviewees appeared more willing to express their feelings about lack of self confidence and success in relationships, and their sadness or anger about rejection. This is possibly related to gender differences in that, for women, 'normal' everyday discourse with close friends at this life stage involves disclosure of feelings, whereas male social discourse perhaps focuses more on fitness, sexual prowess and success.

Overall, most of those who expressed their feelings of rejection had achieved measures of success in other areas of their lives.

8.3.4. Embodiment and intimate relationships

The most potentially challenging issues in intimate relationships, perhaps, were directly related to the exposure of the sexual body and disclosure of health status, including disclosure of the invisible, unknown and sometimes unknowable, manifestations of ERF. Deeply personal concerns about possible infertility and inheritability, not part of everyday discourse or peer relationships, added to worries about the exposure of their 'shameful' bodies. For example, three interviewees (2M
1F) had a known genetic disorder in which no males have been known to father a child and very few females have given birth (Besouw, Kremer, Janssen, & Levchneko, 2010).

Over half of the interviewees had never had a serious intimate relationship. Evidence to this effect was often implicit in what they didn’t say, or came from their mothers. Equally, any assumption, that failure to have a relationship at all, or to sustain one, was attributable to their damaged bodies, was articulated mainly by their mothers.

(Boyfriends?) No, not really... just growing up feeling different ... the hardest thing is, it feels like an unseen disability... I'm not in a wheelchair, I'm not paraplegic... but in a way, it makes it harder because ... I still feel really different. (Sara, 27 RRT 2, F2F)

She's never really had ... a serious relationship ... I know like having boyfriends... there's nobody particular at the moment ... she's very conscious of body ... she's got a hideous scar. (MTanya, 28 RRT 11, T)

She's at an age now where she should have had a boyfriend. She feels that ... with the tubes all over her body ... I can't think that she had a serious relationship, sexual relationship as such... she's had ... so-called boyfriends for a kiss and a hug. She (talks about it) a lot ... the scars that she's got on her tummy, her tubes, the future, that she's going to die quite young. (MAlice, 24 RRT 9, F2F)

Debra talked about her fear of being stigmatised as an illegal drug user if a boyfriend saw her taking tablets; suggesting that, for her, being seen as a 'druggie' was worse than being ill.

I won't tell him straight away. I'll see how it progresses, then ... if I feel like it, I'll tell him. If he's sees me popping a pill then obviously I'm going to have to tell him, 'cos I don't want him to think anything bad of me. (Debra, 27 RRT 4, F2F)

Only Samuel, as far as was divulged, was having a serious intimate relationship while on dialysis. External PD catheters, their taped exit sites, fistulas, neck lines and renal shunts for HD were clearly not 'arrangements' very easily explained, or which made them sexually desirable, to any future intimate partner; nor was Henry's external urine bag. One male interviewee was amongst the very few who spoke explicitly about his intimate experiences, clearly choosing his words carefully.

There was this one girl (Uni X) I felt that I needed to show her that I had 2 plastic tubes coming down, I think she was quite put off ... and I felt a bit upset with her, but ... I thought if a girl showed me that... I'd react in the same way to be honest. (Raj, 22 RRT 16, F2F)
Men talked more about the physical limitations their bodies imposed in terms of, for example, what they could not do as a 'proper' father such as play (football)\textsuperscript{13} with their children.

\textit{If I have kids later on, I can't take them to the park and play football like my Dad used to do with me.} (Mario, 28 RRT 15, F2F)

A particular cause for 'shame' arose from possessing a body which appeared to be, or was, 'sexless'. Amy and Hanna were especially slight and small breasted, although Hanna was only eighteen. Two males were physiologically sexless. Jude had received testosterone therapy to remedy the absence of secondary sexual characteristics, including libido, but this was not a priority for Luther, who was in poor health.

\textbf{Summary}

Being and feeling different presented different problems for those interviewees who had been in, or wanted, heterosexual relationships where the physical embodiment of ERF presented serious issues for sexual intimacy. Few interviewees talked about their experiences of intimate relationships and the role of their bodies directly, but the mothers' data contributed further evidence by describing how their children felt about these issues. Evidence suggested that few had experienced previous sexual relationships, other than those in established partnerships. Few interviewees made explicit references to their damaged body as a sexual body, but for those who did, it was a difficult and upsetting experience. Being on dialysis imposed more embodied constraints on intimacy than being transplanted, but PD was far more intrusive than HD. The experiences these interviewees described were possibly typical, but not all talked about these things in the same way, or at all.

\textbf{8.3.5. Managing disclosure}

The barriers to intimacy both physical/sexual, and open and honest exchange of information about themselves, evidenced above, meant that many interviewees were likely to adopt harm-minimisation strategies to protect themselves from discreditation and rejection in forming intimate relationships, and to preserve their ability to pass for normal, as most had in seeking employment.

\textbf{Timing of disclosure}

Sustaining a relationship on dialysis, especially PD was clearly difficult, and more than one interviewee had decided to wait until they had been transplanted before

\textsuperscript{13} Osteoporosis making bones brittle was long-term side effect of RRT
seriously contemplating it. This had involved a very long wait for several without a living donor.

(I thought) 'I'll have a transplant ... then I can move on, because everything's easier once you've had a transplant. I didn't think it would be 7 years (on dialysis). But, it was probably just because I didn't meet the right person.' (Mario, 28 RRT 15, F2F)

Others spoke about the benefits of establishing themselves as highly valued friends before thinking about partnership, and any disclosure at all.

'I've had friends ... people I know through clinic, I know they've had problems, so basically, most of the girl's that I've been out with ... it's been through friendship first.' (Mario, 28 RRT 15, F2F)

There are times when I think I would be better finding someone on my own ... you build a small relationship, they build confidence in you, then you say ... 'I've had this (illness) for a long time, unfortunately that's how I am'. (Satish, 28 RRT 2 F2F)

However, issues of openness and trust arose for some, and led Luc to feel uncomfortable about how long it had taken him to tell his fiancée.

'It was a long time before she knew anything ... 6 months, something like that, before I let anything slip at all ... on line ... She only found out the full extent ... a month, 2 months ago, and she's been living with me 6 months.' (Luc, 24 RRT 18, T)

Early disclosure, at the start of a relationship, appeared to offer little success in minimising the risk of eventual rejection. However, it meant interviewees had few concerns about unplanned disclosures in their intimate relationships, but lost their carefully sustained 'normal' identity in any shared social network. Laura chose early disclosure, and continued to do this, in spite of feeling it was why she had been rejected at the end of several long-term relationships.

'I tell them (boyfriends)... 'This is what I've got wrong with me. I could go back on dialysis'. I'm completely honest ... there's no excuses then, they know that from the beginning, that's the way I like to be ... (A partner?) I don't think it will ever happen, just because of the amount of boys that have ... (rejected me). (Laura, 30 RRT 19 F2F)

Where interviewees were visibly different from 'normal', they were in a sense already 'discredited', and minor deviance could be exploited, perhaps advantageously, in initiating a potentially difficult dialogue with a future partner. Amy was able to exploit her extreme shortness when she first met her partner on a double blind date; he was her friend's 'date', so she had nothing to lose except her friend. In contrast, Anna was proud of her 'difference', but she didn't choose to disclose how her university relationship ended.
Because of my size, I think he had an inkling, so I just told him ... I’d just received a renal transplant ... I think it was the first date ... I thought, ‘There’s no point in hiding it, ... I’m (so) small there’s got to be something that’s not ... right’ ... It’s something ... you can start a conversation with. (Amy, 24 RRT 7)

(Boyfriends?) the scars ... they’re very obvious ... I had a long-term boyfriend at University and after ... I’m very up front, if people ask, part of me is quite proud ... so people I’ve been involved with in relationships, they’ve always known that about me and it’s ... just not been an issue, I guess ... None of them have ever said anything, (about it) ... being an issue or not. (Anna, 28 RRT 12)

Overall, early disclosure did not appear to protect interviewees from later rejection, but, if interviewees had been totally discouraged by previous experience of partner rejection, then a decision not to have a/another sexual partner was possibly a useful way to prevent further harm to their positive identity, one which allowed them to pass for ‘normal’. This was most useful for those on dialysis who could theoretically look forward to ‘normality’ when/if they got a transplant. A few who were already visibly discredited by a minor ‘abnormality’, found exploiting this was useful in opening the door to fuller disclosure, and possibly less rejection. Similarly, having an intimate/sexual relationship with someone who was already an established friend, possibly offered some protection.

Role of social networks
Community and family networks were important to interviewees in finding an intimate partner, simply by increasing the number of people who already knew about their illness.

(My fiancé is) my cousin’s best friend ... when I first started just going out with him, I said ‘You do know this, this and this’, and he said, ‘Yes I do, but at the end of the day ... I know about what happened in the past, but I wasn’t around then, but I’m here now and I want to ... get to know you’. (Carmen, 24 RRT 15, T)

I’ve known him (my husband) all my life really ... his Dad went to school with my Mum, his Dad used to be best friends with my Dad. (Petra, 30 RRT 9)

Religious or cultural networks were particularly important for interviewees who were members of ethnic groups or faith communities. This was, in part, because they/their family mixed socially within these communities, had gained support from within them, and again, their illness was likely to be ‘common knowledge’. Whilst there is evidence in wider society that more young people from Asian diasporas are seeking to make their own choices around who they marry, many still choose to marry within their cultural group. Three Asian males expected to find, or have a partner found for them, from within their faith community, although this was not altogether welcome and Satish (Moslem) and Ajay (Hindu) felt under family ‘pressure’ to get married.
We're all at home ... what's on their (parents') mind is the marriage side of things ... I want to get married, it's not really pressure, but. (Satish, 28 RRT 2 F2F)

Ajay was financially independent, but lived at home with his parents, and had resorted to subterfuge to avoid parental pressure to marry; Raj (Sikh), younger and still a student, appeared to be happier.

My parents have been trying to put pressure on me to get married, but I'm not going to get involved in something I'm not interested in, I'm not going to rush into anything ... I'm seeing somebody at the moment ... if they found out about her, it would be, 'When are you going to get married?' ... the less they know, the better. (Ajay, 28 RRT 17 F2F)

My parents they, they met on the day of their marriage and stuff... so I am very open to it as well ... I'd be pretty pleased with that. (Raj, 22 RRT 16)

Satish's parents were in active negotiation with a family with a 'suitable' daughter. He explained how, in an arranged marriage, disclosure of illness became a family matter, and any problems related to his poor health, were offset by the partner’s family against the overall advantages of the family connection. This could be seen as an advantage for someone, like Satish, in poor health, however, he had very mixed feelings about it.

There were several practising Christians amongst the interviewees, and one non-practising Jew, Gus. Samuel was a Christian, as was his girlfriend, and Christianity played a central role in his life. The Christian Church was central to Hanna’s life too, and that of her parents, and the source of most of their friends. Carmen’s extended family was Christian, and her immediate family attended church regularly.

The main Chinese community is at Church... most of our friends are from the Church ... In church ... we’re not saying we discourage dating, but ... maybe this is not the right age for dating. (Hanna, 18 RRT 17)

He (my fiancé) was CofE as a child ... he wouldn’t be a church-goer at all, but he doesn’t dismiss the fact that I believe in God, and he does believe as well, he will pray if he thinks ... he needs to. (Carmen, 24 RRT 15)

I haven’t really met any (girls)... I want to marry a Jewish girl, there aren’t any in (town X) … I’m not really interested in (religion), but I like the Jewishness and stuff. (Gus, 25 RRT 22)

Disclosing her ill health to someone she met on a blind date had proved successful for Amy (see 8.3.5). Disclosure via the internet similarly offered similar possibilities of early disclosure to a stranger, and correspondingly fewer feelings of personal rejection. Three quarters of interviewees said that access to the internet was important for them (Appendix 3, Table 41), but only a few (all male) mentioned it in
the context of finding a partner, perhaps because it was seen as potentially unsafe by the female interviewees. Most interviewees used it only for information, jobs, social chat and/or support (Appendix 3, Table 29).

Three male interviewees had found partners via the internet. Luc, recovering from depression, spent a lot of time on an internet social site where he serendipitously found his future fiancée who lived in the UK, hundreds of miles away.

*I met my girlfriend on line ... we happened to get on really well ... it were like ... a year and half after we started talking (on line) that we met up, and she's living with me now.* (Luc, 24 RRT 18, T)

Mario joined a 'special interest' site, and had recently become engaged to someone in the Far East whom he had visited twice ... had met her parents, and overcome language barriers and opposition on health grounds. Fortuitously, his fiancée's sister was a renal nurse.

*A friend said, 'There's this website, pen pals', so we became pen pals, and ... gradually got to know each other ... I went over and stayed with her ... and now we're engaged.* (Mario, 28 RRT 15 F2F)

There was possibly some social stigma attached to internet dating sites, and Jerry, who had met his fiancée this way, felt the need to explain that he had moved geographically and found it difficult to establish any social life in a new location. Two other male interviewees had tried on-line dating: Jon described it as a 'waste of time', and Jude had looked, but didn't feel 'ready' to try.

*I didn't have any (girlfriends) throughout school, college. First few years living down south ... I didn't know anyone my own age. ... at first it was, well I've got nothing to lose, I'll just ... see what happens. Anyone I spoke to I was honest with and didn't try and hide what was wrong with me ... I think I had about 2 others before I met my current girlfriend, my fiancée.* (Jerry, 25 RRT 12, T)

**8.3.6. Summary**

Very few older interviewees were living with an intimate partner, although a few had previous experience of intimate partnerships, and some were in committed relationships. The stigma of ERF, insecure identity, embodiment of RRT and previous rejection, all made disclosure of ERF illness status problematic in intimate relationships, especially for those on dialysis. A relationship with someone who already knew about their health history, via their own or their family's social networks, served to protect interviewees from rejection. These networks helped interviewees meet potential partners in settings where initial disclosure was less of a problem, overcoming a first barrier to full disclosure. Extended social networks based on
religion or culture proved especially helpful. Self-discreditation to ‘strangers’, via the internet or a blind date, helped protect their positive sense of self, as rejection felt less personal.

8.4. TRANSITION INTO PARENTHOOD

Most interviewees said they wanted children, but the possibility that they were infertile, and/or unable to have children, raised many different concerns.

_I would love them, but, there’s all the things ... Would you pass it onto them? What happens if you’re ill and you can’t look after them? What if you die and then there’s nobody there for them?_ (Laura, 30 RRT 19)

8.4.1. Longevity and parenthood

Most interviewees had every reason to expect a reduced life-expectancy. Few interviewees referred explicitly to this in the context of intimate partnerships and having children, but Tristram had clearly spoken with his mother about this. Daniel was one of very few who mentioned dying directly, and Hanna less personally.

_There’s the life expectancy bit … do you have kids and then … you’re not going to be there to see the job out … knowing that you might … die half-way through, that’s probably the biggest thing for me._ (Daniel, 27 RRT 10, F2F)

_This boy … (said) … he liked this girl who has epilepsy … (and) his Mum … said, ‘Oh we don’t want grandchildren who have problems’. I was thinking, it’s just epilepsy … you can have it under medication … If that was me, maybe in-laws would think, ‘Oh I don’t really want her ‘cos she might die._ (Hanna, 18 RRT 17)

Others in relationships did not mention such fears, possibly assuming they would be around to see parenthood through, albeit in poorer health.

_I’d love to have children … with the right person … I’ve thought maybe … of my children asking why I’ve got scars all over my body and things like that … I’ve not really considered it in terms of (longevity) … I think I’ll still be around, but I think my quality of life might not be as good._ (Ajay, 28 RRT 17)

There was huge variation in the views expressed here, many men tended to talk about ‘getting on with it’, in contrast, the female interviewees tended to worry; Luc was an exception here.

_We’ve talked about it and my girlfriend would like (children) … but I probably get a little bit more worried about the future, than I tend to let on._ (Luc, 24 RRT 18)

All the interviewees had been confronted, in the adult renal hospitals, by a picture of their long-term future on RRT. However, how long they might live and who might care for them when their parents were no longer alive was not a subject many of them
raised. While there were some worries from interviewees and their parents about longevity, only two interviewees mentioned, or alluded to, the burden of care that might fall on the shoulders of anyone who loved them and entered into an intimate relationship with them, or any effect of their death.

I like being self-contained ... in my emotions when I'm going through ... difficulties. I don't like putting that burden on other people ... and I've never ... found the right person ... or a female ... to bring that sharing completely ... I'm pretty confident I will ... but until you find that sort of almost trust ... you don't want to put someone through all that if ... you know you don't want to be with them for much longer. (Edward, 30 RRT 7)

It's easier having a transplant and having a girl friend than what it is on dialysis and having a girl friend 'cos you don't feel so much of a burden. (Kieren, 29 RRT 7)

Being a burden was mentioned by two in the context of the parental burden.

A child who's sick in a family ... I think, always grows up with a feeling of ... being a burden, even if it's not particularly rational thought ... I wasn't even sure that at first if I wanted (Mum's kidney) ... because I had 3 sisters to think ... it felt like a huge burden to say 'yes' to something like that. (Sara, 27 RRT 2)

In a sense my family take the burden of my illness ... My Dad had a bit of ... depression ... I think he did actually go and see someone, I think because it was because of ... burden of me. He felt he was powerless. (Millie, 26 RRT 16)

Interviewees' parents talked more generally about the burden they carried and about how carrying it silently was integral to maintaining a semblance of a normal life for the interviewee and the family. Marian's mother articulates below the concerns other mothers expressed about transferring the burden to another person.

I mean she's got a boyfriend ... he's been brilliant all through it, but I don't know if he fully understands... the long-term implications. (MMarian, 19 RRT 16)

I feel that I (carry the burden) whether or not I do ... I know her Dad ... worries about it, but he doesn't ... talk about it, 'cos that's his way ... I want everybody to treat her as a normal teenager ... I don't want them to ... see her as being different ... so the less I say about how worrying it is, the less they'll think (MMarian, 19 RRT 16).

However, for the mothers as well as the interviewees, keeping silent led to less support.

8.4.2. Reproductivity, gender, and parenthood

Gender differences were important. Most of the men lived with the possibility of infertility, and most did not know whether they could father a child (except Marc who had fathered two boys). Male infertility was discussed at clinic, but doctors could not offer as much reassurance as they needed. Several voiced such concerns, but they
were not uppermost in their minds, as few were in partnerships. Those that were in heterosexual relationships tended to assume that all would be well.

You don't want to (find out) the day before you get married ... you're with someone who doesn't want children if you do. I do remember being told ... there's normally no biological problems ... to have kids. I've never actually looked in to it, so I've just presumed that it's all OK. (Mario, 28 RRT 15)

We have talked about (children) ... she's ... crazy about babies for some reason. (Worries?) 'Not really, she thinks I'd make a good father' ... I get on with it, I don't think differently just because I'm on medication, or I've got a transplant. (Eugene, 29 RRT 9)

Jude alluded to the limitations of his recent testosterone replacement therapy, but it was his mother who described how his appearance, at the time of interview, was less 'genderless' than it had been as a teenager, and her perceptions of Jude's feelings about lagging behind his peers in finding a partner.

I can't have children ... but, there's different ways, aren't there? (Jude, 22 RRT 10)

Hormones ... for facial hair and stuff, to deepen his voice, that's helped quite a lot ... He doesn't like to talk about it ... I think if he found a girl, life would fall into place ... all his friends are pairing off ... he said 'I just want somebody to love me for me'. (MJude, 22 RRT 10)

Motherhood, or the possibility of motherhood, raised specific fears and concerns for the female interviewees. Rumour, hearsay, and mixed messages from hospital staff, played a part in undermining female interviewees' confidence in their fertility, but most worried not only about fertility, but also about the impact of pregnancy and child birth on their own health, and that of their transplanted kidney, where present. Some had justifiable fears of mortality, and those on dialysis were aware that there were very few reported cases of successful child birth in dialysis patients. Laura raised a different issue, that of her 'duty of care' to the kidney donated by her father.

I've also heard ... (having children) can put your kidney at risk and ... because it's Dad's, I wouldn't put it at risk. (Laura, 29 RRT 19, F2F)

I'd love children, but... I don't want to risk it ... I'm going to push (my body) to the limits if I have a child ... (pregnancy) causes ... antibodies, it causes problems, I'm basically risking it to kill myself ... it's quite a big thing, especially with me being so unlucky with my illness. (Alice, 24 RRT 9, F2F)

Those who had children (2) had experienced difficulties in pregnancy and childbirth.

They said (my daughter) was going to be born disabled, because I was on this new tablet and they hadn't tried it on pregnant women ... she was 2 lb 8 ounces. (Petra, 30 RRT 9, T)
I'm not sure if I can put my body through (pregnancy) again ... They found the DVT in the leg ... things the doctor was saying ... was really freaking me out ... 'If that travelled ... into your lung ... your heart' ... I would like a girl, but ... I might have to be happy with (son). (Debra, 27 RRT 4, F2F)

Several female interviewees were trying for a baby without success, and for this reason, several were seeing a gynaecologist. Millie was told by her nephrologist to wait until she had another, better functioning, transplant, but chose not to take 'precautions'. By allowing chance to play a part, she was taking a risk with her health, raising issues related to finding the 'right' balance between agency and 'compliance'.

The hardest thing is ... when your younger friends start having them ... I've got friends 22, 23, and they've got children. I think 'Will it ever happen?' ... You just (want) that little glimpse of hope, you might one day wake up and be pregnant. (Millie, 26 RRT 16, F2F)

I've ... been to see a specialist at (X) about it. They said, there's no problems ... I probably wouldn't be any more affected than any other woman. (Lucy, 27 RRT 9)

As in wider UK society, female interviewees with/wanting professional careers perhaps wanted children at later age than more working class females.

I can't wait to have kids ... I'm currently single, I'm not looking to have kids right now, but in the next 5, 10 years, I would like to start a family ... So is a (2nd) transplant operation going to affect that ... is it going to complicate pregnancies? ... extra things that I have to worry about? (Anna, 28 RRT 12, F2F)

Inheritability

Six interviewees knew they had inheritable diseases. Three had cystinosis (autosomal recessive\(^ {14}\)), including Petra, Amy had a rare autosomal dominant genetic disorder\(^ {15}\), and Hanna had inherited polycystic kidney disease\(^ {16} \) from her father. Petra had had a baby with some difficulty, and Hanna was very young; but Amy (whose sisters had the syndrome) did not appear to be taking inheritability into consideration in her future plans with her partner.

Children is a definite, if possible ... The only issue at the moment is ... we don't think I will be able to get pregnant ... If we can't ... then it will be another option, because we definitely want kids, whether they're our own or not. (Amy, 24 RRT 7)

However, some interviewees had no diagnosis beyond ERF (Table 4.6) and no idea whether their condition was inheritable. This issue had raised huge questions for

\(^{14}\) Two copies of the faulty gene are needed for it to be expressed in phenotype

\(^{15}\) Only one copy of a faulty gene is needed for it to be expressed in phenotype

\(^{16}\) Usually autosomal dominant
Daniel (recently married) and whose sister had recently been diagnosed with ERF: ‘they’ did not know whether this was due to genetic or ‘environmental factors’.

We’d love kids … if four arrived tomorrow I would love it … but … do you pass the problem on? … We’ve been to see geneticists when (sister got ERF) … I thought it would be more comforting to know that you were just a freak, things just hadn’t quite got right, so fine. (Daniel, 27 RRT 10, F2F)

Inheritability was less of an issue for those with one of the most common causes of ERF, undiagnosed structural disorders of the urinogenital system at birth which often cause reflux of urine from the bladder to the kidney.

‘Cos I had reflux, they say, even knowing my children could get it … they’d look out for it, and it can actually be treated, apparently with antibiotics. (Lucy, 27 RRT 9)

Adoption

Five female interviewees talked about adoption. They saw this as safer than having their own child.

I did say to my Mum, ‘I’m warning you that I might not have my own children, I might adopt… ‘Why do I have to have my own child? Isn’t the child that I’m going to adopt the same thing? Am I still not going to be mother?’ (Alice, 24 RRT 9)

If someone tells me I can’t have kids … that will be the breaking point … for me. I think you’ve got to be a very strong person to adopt … (my partner’s) attitude is, if we can’t have it ourselves … he doesn’t feel he could take on responsibility for something that’s not his own. (Millie, 26 RRT 16)

We looked into adopting after (miscarriage) … the (health professional) said, ‘You’re on aspirin, you’ve had a stroke already … I wouldn’t advise it’. (Petra, 30 RRT 9)

8.4.3. Summary transition into parenthood

Transfer from paediatric to adult care had raised all the interviewees’ awareness of their long-term health and mortality, but this was clearly a difficult topic to discuss. More men mentioned longevity constraints than women, who focused on more personal immediate concerns (around parenthood). Several interviewees showed an awareness of the burden of care their families had borne, but few the burden that any future partner might bear.

Interviewees appeared to find it easier to voice their fears and worries about becoming a parent than their limited lifespan, or the difficulties they had experienced/were experiencing in finding a partner, perhaps because they were less personally intrusive, and had been the subject of discourse with health professionals.

8 Vesicoureteral reflux: urine flows from the bladder back up to the kidney. It causes infections in the urinary tract, which if undetected or frequent, lead to scarring and disease in kidneys
Gendered aspects of embodiment and reproduction were highly salient. Not all the original diagnoses were known, and it was not clear how many interviewees had an inherited and inheritable condition. However, for those that did, it presented an added anxiety. Only one male, recently married, appeared seriously concerned, because it appeared likely that his renal failure was inherited. Several others of both genders knew they had an inheritable condition, and would have been advised of the implications.

The possibility of infertility was raised by only one or two males, and most had not thought about it, but overall males had fewer clinical reasons to worry about reproduction and childbirth than females. The older female interviewees were clearly worried about fertility, as well as the dangers of pregnancy and childbirth. Even for female interviewees with well-functioning transplants, there was medical concern, and some evidence, that becoming pregnant might put too much strain on either their transplants and/or their own bodies. This had been very real for the two mothers, in terms of threats to their own lives, their transplants, and for one, the risk of damage to the unborn child from drugs. Several were seeing gynaecologists because they were experiencing difficulties in conceiving.

A question mark over whether or not she should become a parent had contributed to relationship breakdown for Laura, and several females were thinking in terms of adoption rather than risking their health, as it appeared to offer a way to resolve anxieties associated with pregnancy and child birth. However, it represented a highly constrained choice for some.

Female attitudes to motherhood reflected recent changing attitudes in society. The highly educated female interviewees talked more about their education and careers, delaying consideration of pregnancy and child birth, while more working class females, with less interest in their career, were impatient to have children.

8.5. SUMMARY

Some of the challenges faced by the interviewees in leaving home and finding an intimate partner were no different from those faced by other young adults, except in that their lives were expected to be shorter. However, the data suggested that their illness, in most cases, tended to exacerbate whatever challenges might have arisen from their family background, social class, religion, and/or geographical location.
8.5.1. Critical moments
Episodes of acute ill health had disrupted some interviewees' lives at the 'critical
day' moment' of leaving the parental home, and shared independent living arrangements
had broken down for several when they became ill. Moreover, a legacy of difficulties
with childhood peer relationships had left some with limited social skills, limited social
networks and problematic social identities, which perhaps made it difficult to find
people with whom they could share accommodation. In their partner relationships,
many found the first disclosure of their illness, intended or unintended, was another
such critical moment that changed the trajectory of their lives at that point.

Social capital and social class made a difference, so that more middle class highly
educated interviewees lived independently, but overall, for many, especially the early
onset group and/or those in poorer health, their lives became increasingly different
from those of their own peer group, who had perhaps been relatively more successful
in education, employment, and who lived independently, and/or had found a partner.

8.5.2. Embodiment, stigma and disclosure
A high proportion of interviewees lacked confidence and over a third found it difficult
to talk about themselves. Many described previous experience of having been
rejected by intimate partners and this undermined their confidence in seeking new
relationships. Most 'passed for normal' and found it difficult to discuss their illness at
all, so at some point in any new intimate partner relationship, they had difficult
questions to answer, and needed to raise very difficult, personal, intimate matters. In
addition to the more obvious areas of the embodiment of ERF already discussed in
the context of friends and employers, different viscerally embodied aspects of their
disease became more salient. Questions about fertility, real and perceived dangers of
pregnancy and childbirth, inheritability, reduced life expectancy, and fears of being a
burden, had to be addressed. Equally, if not more difficult, was the exposure (or
thought of exposure) of normally hidden parts of their body to critical gaze in a sexual
relationship. They feared that their damaged bodies would engender feelings of
revulsion in an intimate partner, and lead to rejection and erosion of any positive
sense of self.

Thus, interviewees' bodies, and their feelings about their bodies, presented real and
tangible barriers to intimacy, especially sexual intimacy, which made it hard for them
to feel confident in their gender-specific sexual identities as sexually desirable young
adults. For most who were discreditable, it was perceived stigma, derived from their
own fears of discreditation and rejection, more than enacted stigma, that influenced their behaviour and attitudes to potential partners. Only one interviewee talked about revulsion from a sexual partner directly.

Three quarters of the interviewees thought it was important to have an intimate partner. However some of those who had been rejected found it adversely affected their approach to any future relationships, and decided against having intimate relationships for some prolonged time. Several of those on dialysis had also decided not to look for a partner until they could more successfully 'pass for normal' when/if they got a transplant. These choices were constrained by their need to protect their fragile positive identities.

Interviewees who had found partners (engaged or cohabiting) were all, except one, transplanted, and most had found their partners via harm-minimising routes such as local social networks, including faith communities, where they were already known, or by less personal routes, such as the internet. Early disclosure of health status was not a helpful strategy in sustaining intimate sexual relationships, but it helped to avoid the stresses of being constantly at risk of discreditation.

Overall, while some interviewees gave emotionally laden accounts of their experience of finding an intimate partner, few talked about how they felt about their physical bodies in this context. The mothers' accounts offered insight into the depth of feelings many interviewees were probably suppressing, both in terms of presenting themselves to the interviewer, and in 'passing for normal' in their social relationships. The toll this took on them was varied, but probably accounted for much of the depression and social isolation about a quarter of them experienced.

8.5.3. Gender

There were gender differences in the independent living arrangements of the interviewees. All six living alone were male, which was likely to be a constrained choice, as it was possibly harder for them to find an intimate partner. Several had turned to the internet for help. Furthermore, the males from the Asian community expected 'help' from their family. The females living independently of their parents lived with a friend or partner, most near their parental home, suggesting that more females felt, or were willing to admit, they needed the support of friends or family.

The interviewees talked about their experiences of intimate relationships and how they managed their relationship difficulties in ways which reflect the kind of gender
expectations and roles still prevalent today. Male interviewees, on the whole, distanced themselves from any emotional response to partner rejection, and talked about their difficulties more objectively; it was their mothers who provided much of the emotional dimension to their own accounts. However, the stigma attached to unemployment and failure to fulfil their gendered role as provider, led some males to express themselves more emotionally. In contrast, the female interviewees provided more feelings-based accounts. Some expressed their feelings about being rejected by partners strongly. Several had decided not to consider intimate relationships at all for a period of their lives.

Reproductivity was an issue for many of the interviewees in partnerships, who all wanted children. The young women expressed anxieties around their fertility, and the risks to themselves (and any future baby) of pregnancy and child birth. These anxieties were of such serious concern that some were considering adoption, clearly a constrained choice. The male interviewees had parallel concerns, related to their ability to father a child and the inheritability of the condition, but most talked more about their future role as a father. More males appeared concerned about their longevity, and being a burden on a future partner, than females, which is consistent with their male 'provider' role.

Overall, challenges in heterosexual relationships (no same sex intimate relationships were mentioned) and parenthood seemed to be key issues for almost all except the very youngest interviewees and those in poorest health. The evidence clearly demonstrates that the physical embodiment of ERF presented both real and perceived barriers to 'normal' adult intimate relationships and parenthood.

8.5.4. Agency

Few interviewees were as independent as they wished to be, and most felt their intimate relationships and future lives were constrained. Their capacity for agency, to act to change their lives, to find/choose a partner and build an intimate relationship, was reduced by both the legacy of childhood ERF and their discreditable or discredited physical body. Several of the older interviewees were acutely aware of the passage of time, and that they were falling behind their peers in crucial aspects of their adult social lives: leaving the parental home, finding an intimate partner and having children.
8.5.5. Summary

Biographical disruption at critical moments in childhood/adolescence affected the interviewees' progress towards independent accommodation and finding an intimate partner. Not all, but crucially many, of those who were ill before puberty, were disadvantaged by delayed academic achievement and difficulties in employment, so that they had insufficient secure income to move away from the family home. Very few were in extremely poor health. However, many interviewees' adult identities were 'partial' and fragile, and some lacked the self confidence and resilience which are crucial for managing the kind of rejections that are part of everyday social relationships and seeking close intimate partnerships. More success in achieving other goals of adulthood might have given them a more positive sense of self, and more secure social identity as an adult to cope with rejection. Most wanted an intimate partner and children, and some of the older interviewees had found partners, but only three had children. Many more were single, and some of these saw almost insuperable barriers to intimate relations.
9.1. INTRODUCTION

This chapter aims to show how the findings from this study address gaps in existing sociological knowledge and theoretical perspectives on chronic illness experience. It will do this by incorporating the experiences of young adults with a particularly uncertain and largely invisible chronic illness (ERF) into academic discourse on marginalised youth transition into adulthood, and into current understandings of the chronic illness experience across the life course, especially with respect to chronological age, age of onset of illness, biographical disruption, identity and embodiment. It will also examine the role that social resources in the family play in shaping the transition experience for young adults with chronic illness. Methodologically, it draws on interview data from young adults with ERF and their parents, and data from the survey from which the interview sample was drawn.

9.1.1. Limitations of existing research in this field

Youth transition has been described as a process or a journey, rather than an event, and various metaphors have been used over time in the qualitative literature to depict this. Evidence also exists to show that this process, for all young adults, now occurs over a much longer time period than it used to in the mid 20th century (Brannen & Nilsen, 2002; Thomson, Bell, Holland et al., 2002), in part due to the increasing complexity of society, fragmentation of the life course, and the diversity of the choices facing young adults. Although little youth transition research examines transition for young people who are chronically ill (Evans, 2002; Galambos, Darrah, & Magill-Evans, 2007), more work exists in the disabilities field (Leiter & Waugh, 2009), and a recent UK survey of life opportunities for adults with disabilities (ONS, 2010) illustrated that all respondents experienced at least one social barrier to participation in society.

Youth transition literature has identified different kinds of markers of adulthood and measures of progress towards adult status. These range from easily measurable markers, such as educational attainment, employment, independent living, income, family formation and establishment of intimate relationships, to more difficult to measure subjective personal markers and measures of identity development (Arnett, 2000, 2001, 2004; Benson & Furstenburg, 2003; Fadjukoff, Kokko, & Pulkkinen, 2007; Leiter & Waugh, 2009; Shanahan, Porfeli, Mortimer et al., 2005). The concept
of 'emerging adulthood' (Arnett, 2001) has proved useful in recognising that transition to adulthood continues from adolescence into the late twenties, and that attainment of education, employment status and independent accommodation may be less important today, than achieving 'softer' goals related to developing secure adult identities, individual beliefs and values, personal responsibility and independence.

Extensive psychosocial medical research into a range of chronic illnesses in adolescence has been conducted by health care professionals aiming to improve health and care outcomes. This has focused mainly on psychological coping and/or adherence to treatment. However, qualitative sociological work on chronic illness in childhood and emerging adulthood is limited, and there is little literature which explores how social resources are used by young adults with chronic illness, compared with the large body of research which explores socioeconomic determinants of more common diseases, such as depression, heart disease, cancer, and stroke.

9.1.2. Methodology

Three sources of data have contributed to the findings from this study: quantitative survey data from 296 respondents to a survey of all hospital patients, aged 16-30 inclusive, on RRT in 14 participating hospitals, qualitative data from 40 interviewees recruited from the survey respondents, and qualitative data from 20 interviews carried out with their parents, mostly mothers. The similarities and differences between the patient qualitative and quantitative data allowed critical examination of the qualitative findings, and interview data from the parents offered insight into the young adults' data, and provided a picture of the emotional work mothers (especially) had done in supporting their children, some for more than twenty years. The accounts of the parents were mainly accounts of suffering, in contrast to those of their children, whose accounts suggested they were more concerned to present themselves positively.

The survey data demonstrated that the lived experiences of young adults, discussed in the analysis chapters, were shared by many survey respondents. Quantitative data analysis showed that chronological age of onset made a significant difference to attainment of several adult markers in that those who were ill in their early years had lower levels of attainment than those who were ill aged 16 and over. Analysis also illustrated the uncertainties and complexities of RRT and the kinds of issues and challenges respondents faced, providing further evidence that the age at which they first became ill made an important difference to their lives as young adults.
ERF is a rapidly deteriorating condition, terminal within a short period if not treated, and it is therefore essential that renal replacement therapy (RRT) begins immediately on diagnosis. It is rare in children, and until the late 20th century, children whose kidneys failed did not survive. Thus the young adults in this study with ERF, like those with cystic fibrosis (Foster, Eiser, Oades et al., 2001; Lowton & Gabe, 2003a; Sanders, Gravestock, Wanstall, & Dunne, 1991; Steinkamp, Ullrich, Muller, Fabel, & von den Hardt, 2001) and young adult males with DMD (Gibson, Young, Upshur et al., 2007; Gibson, Zitzelsberger, & McKeever, 2009), have been described as 'first generation adult survivors' (Blum, 1995 p 4).

In this section the childhood and transition experiences of young adults with ERF are discussed in terms of how far previously elaborated sociological concepts related to chronic diseases (biographical disruption, identity and embodiment) (Bury, 1982; Charmaz, 1983; Kelly & Field, 1996) are applicable to young adults with ERF, and in particular, how far they accommodate the subjective chronic illness experience of this age group, especially where ERF occurs before puberty. Most interviewees produced mainly contingent or moral narratives, characterisable as heroic or progressive, determined to show progress towards personal goals. Fewer than a quarter produced accounts which were tragic and/or regressive, acknowledging that their personal goals had become less attainable (Bury, 2001; Robinson, 1990). This balance was perhaps related to their age and a need to present themselves positively to the interviewer (Goffman, 1959).

9.2.1. Critical moments for biographical disruption
The most striking feature of the interviewees' accounts was the degree to which all their lives were repeatedly interrupted by episodes of acute illness, long after the original diagnosis. However, the age at which they began RRT, and the timing of subsequent severely disruptive events during their lives, appeared to be particularly salient in terms of gaining an understanding of the meaning of ERF for the interviewees, as it was for young cancer patients and other disadvantaged young adults (Grinyer, 2007; Thomson, Bell, Holland et al., 2002). Puberty has been identified as a crucial time in that ERF before puberty had a greater effect on the attainment of measurable goals of adulthood, and more intangible goals related to personal autonomy and identity, than ERF after puberty.
'Beginnings' were important, critical moments (Holland & Thomson, 2009; Thomson, Bell, Holland et al., 2002), when the interviewees' illness more obviously impacted on their future lives. Some missed the beginning of a new school, a new school year, or their post 16 education and training. Any or all of these adversely affected their peer relationships and their educational attainment, especially illness at school entry aged 4/5. Similarly, missing the beginning of a university course meant both academic work and social relationships suffered. Examination times were similarly critical, especially external examinations such as GCSEs, A level and Degree finals, either because of missed coursework and/or missed examinations. Such critical times have also been depicted, more theoretically, in individualisation theory, as 'fateful' moments which present choices that are highly consequential for future lives (Beck, 1992; Giddens, 1991).

Irrespective of the age of onset of ERF, the period between leaving education and becoming employed, was experienced as a critical time. Being ill shortly after starting a new job meant one interviewee was dismissed by his employer, for another, his contract was not renewed. Interviewees, who were well-established/highly regarded at work when they became acutely ill, were mostly better supported by their employers. Finding paid work proved difficult for some and many accepted any kind of paid work rather than work they wanted to do, or remained unemployed.

Family breakdown has long been recognised in families of children with disabilities (Leiter, 2007; Shandra, Hogan, & Spearin, 2008). The stresses ERF imposed on family life were enormous, but experienced more acutely the earlier the age of onset, and where social capital was limited. In families where the interviewee was older and more independent when they first became ill, no family breakdown was reported. For many who were ill as young children, family breakdown came at a critical time in their development (Bee & Boyd, 2009; Stillion & Papadatou, 2002).

9.2.2. Uncertainty

Some of the uncertainties associated with ERF found in this study were similar to those experienced by other young adults with different serious chronic illnesses in childhood (Grinyer, 2007; Kazak & Nachman, 1991; McDonagh, Southwood, & Ryder, 2000; Myers, 1992; Perez, 1997; Scambler & Hopkins, 1986; Seppala, 2002; Stam, Hartman, Deurloo et al., 2006; Williams, 1998), but the unpredictability and instability of the main treatment modalities, and the ensuing severity of the disruption to their normal lives from diagnosis onwards in ERF, might be regarded as unusual (Kierans, 2005; Summer, Stone, Scott et al., 2010).
Unlike some diseases of childhood, such as DMD, where deterioration of health is progressive in spite of treatment (Gibson, Zitzelsberger, & McKeever, 2009), ERF is characterised by dramatic improvements and sudden reversals of ‘health’, as RRT modalities succeed or fail. The medical and surgical technologies involved in ‘shunting’ the interviewees back and forth between relative ‘health’ with a transplant and ‘illness’ on dialysis, were experienced as extremely distressing events with uncertain outcomes. Although some interviewees were aware, and not all were, that their renal health was deteriorating, the moment at which health professionals decided a surgical intervention was necessary was highly unpredictable, and was usually a shock.

A few other diseases affecting young adults, among them sickle cell disease (SCD) and cystic fibrosis (CF) (Atkin & Ahmad, 2001; Gibson, Young, Upshur et al., 2007; Grinyer, 2007; Lowton & Gabe, 2003a), share the uncertainties of being shunted back and forth from relative wellness to relative illness, whilst being wholly dependent on medical technology for survival. Among them, the highs and lows of transplantation, be it kidney, lung, heart, liver or pancreas, might well be unique. Lowton and Gabe (2003a) captured these by describing how CF patients (aged 18-40) moved from normal health, through health as ‘controllable’ and health as ‘distressing’, to health as ‘release’. So-called ‘release’ came from successful transplantation. However, in ERF transplant failure leads to a return to ‘health as distressing’ on dialysis, whereas in CF, there are no other organ replacement technologies.

Several interviewees talked about the uncertainties surrounding their future lives in terms of longevity and mortality (Locock, Ziebland, & Dumelow, 2009), subjects difficult to discuss (Stillion & Papadatou, 2002), but more admitted to worries about the future in their survey responses. Those who mentioned their own mortality were mostly male, and most referred to it in impersonal language or euphemistically. More talked about the future of their kidney transplant, mirroring medical discourse, which prioritises graft survival rates over patient survival rates in reporting statistical data (UKTransplant, 2011), and reflecting acceptance of medical models of health (Helman, 1985; van Teijlingen, 2005). Transplanted interviewees described how they worried about graft loss, but more in the sense of losing their ‘normal’ life, than losing their lives. However, a major, but largely unspoken, source of uncertainty about life expectancy was the dwindling of future treatment options for some (both retransplantation and dialysis access), and most knew they faced a relatively high
risk of sudden death. Additionally, because kidney failure is an outcome, not a primary 'disease', several lived with the uncertainty and implications of not knowing why their kidneys had failed.

9.2.3. Bounded agency

Young adulthood is a time when young adults are increasingly seeking independence, autonomy and control over their own lives. Interviewees with ERF found that they were able to exert little control over their own health, and that their agentic power to influence other aspects of their own lives was 'bounded', like so many disadvantaged young people (Evans, 2002), by social structures and social resources. Some researchers have argued that in order to gain/regain a sense of empowerment and control in life with chronic illness, and for sick and well identities to be reconciled, it is necessary to accept loss of control of 'life', at the same time as gaining control over aspects of illness or treatment (Aujoulat, Marcolongo, Bonadiman et al., 2008).

Resistance to medical treatment advice has also been conceptualised as agency (Koenig, 2011), but arguably scope is very limited in ERF. Interviewees could choose whether to follow medical advice to keep themselves physically fit or follow a healthy diet, but the latter often conflicted with the eating behaviours of peers and associated social acceptance (Stead, McDermott, MacKintosh et al., 2011). Most took, or had taken, risks with their health, drinking to excess sometimes, missing their medication, missing dialysis, ignoring dietary restrictions (activities seen as 'normal' at this life stage), and had chosen to 'live for the moment', perhaps being fatalistic. Such risk-taking was deplored by renal staff, and has jeopardized the lives of many young patients (Laederach-Hofmann & Bunzel, 2000; Rapisarda & Tarantino, 2004; Rianthavorn, Ettenger, Malekzadeh et al., 2004; Wray, Waters, Radley-Smith, & Sensky, 2006), including some interviewees, at a younger age. Exerting choice about whether to 'try for' a baby in the face of medical advice to the contrary, offered agency for some, but was a high risk strategy.

Moreover, there were few occasions when a change in RRT could be planned in advance, or choices made, except in choosing dialysis modality (PD or HD), living donor transplantation, or deciding to join the transplant waiting list. Equally, there was little interviewees could do to avoid premature death from ERF, except follow medical advice; slow deterioration of their cardiovascular system was inevitable. In terms of the kind of metaphors used to describe life course trajectories, the lived experience of
ERF might be described as disempowering, a 'roller coaster' ride downhill, as some survey respondents reported.

9.2.4. Age, chronic illness and identity development

'Identity' itself is a problematic concept in sociology and there are many theories about how identities are developed. The most useful for this study appear to be based on how identities are developed through social relationships, self reflection and biographical narratives (Charmaz, 1983; Giddens, 1991; Thomson, Bell, Holland et al., 2002). Shilling (1993) usefully identified the differences between an individual's social identity, the image other people have of them, and their self identity, their sense of self. Charmaz (1983) classically described how contracting a chronic illness meant the loss of a previously known self, and that previous positive self images were not replaced by self images that had value for the sufferer.

People with ERF experience complex identity challenges (Summer, Stone, Scott et al., 2010). Transplantation itself raises issues of identity, especially where body parts such as face and heart are transplanted (Edgar, 2009). All the interviewees, except one, had a mass of 'foreign' tissue, someone else's kidney, 'plumbed in' to their abdomen. None seemed to find the graft itself presented an identity issue, perhaps again because they accepted the medical model, much criticised academically (Engel, 2004; Williams, 1984), but inherent in their own experience of medical discourse.

This study confirms that identity challenges associated with chronic illness are experienced differently where biographical disruption occurs early in life, especially before puberty (Hartman, DePoy, Francis et al., 2000). Most interviewees who were ill from early childhood (12 were ill before 8 years) appeared to remember nothing, from those very early days, other than being a 'renal patient'. Early childhood illness identities had developed from being labelled as a renal patient by health professionals (Leiter, 2007), and become embedded by repeated prolonged usage. This labelling was rejected by many in adolescence, and a more 'normal' identity assumed, as reported for others on RRT (Tong, Morton, Howard et al., 2011).

In contrast, several of those who became ill at puberty or later talked about how they had lost their previously well selves. Whilst they were identified as kidney and/or renal patients in hospital settings, most endeavoured to reclaim their pre-illness identity in everyday life. After transplantation, some of this group of interviewees felt that the 'promise' from doctors of a 'return to normal' life (Crowley-Matoka, 2005) had
been delivered, and felt able to present themselves positively with a 'normal' identity, initially less aware of future uncertainties. Others, whose first transplant was not successful, were frustrated or angry that the transplant had not returned them to 'normal life', and they faced a very long wait on dialysis for a cadaveric graft, several in poor health. A few then presented themselves as 'ill'. Waiting times varied enormously, but the three year average, represents, proportionally, a long time in the life of a young adult, much longer than for someone who has lived more than sixty years, for example.

9.2.5. Gender and age identity
A particular identity challenge for most of those experiencing ERF in early childhood related to their failure to grow and develop normally. Most grew up feeling and looking different from their peers with an increasing awareness of being 'abnormal'. Many interviewees described being teased, bullied or otherwise discriminated against at school, as had children with sickle cell disease (Dyson, Atkin, Culley et al., 2007). Abnormal smallness of stature appeared to be more problematic for the male interviewees, than for the females.

Adolescence and emerging adulthood are times of experimentation when most young people are experimenting with leisure, drugs and sexual experiences (Arnett, 2004; Arnett, 2005). For the interviewees, engaging in these 'normal' age-related social activities compromised their renal health. Alcohol and illegal drugs were dangerous, sharing food was problematic (Stead, McDermott, MacKintosh et al., 2011), and they were more at risk of sexually transmitted diseases, if immunosuppressed. Many prepubertal onset interviewees were also developmentally delayed at puberty, and sexual differences from their peers made adolescence more challenging for them because of their relative physical, sexual and emotional immaturity.

Male interviewees, especially, discussed how they were seen and/or regarded by others as too young or too immature to be young adults, as reported for adolescents with physical disabilities (Stewart, Law, Rosenbau, & Willms, 2001). Their small stature made it harder to form peer relationships based on physical activity (de la Haye, Robins, Mohr et al., 2011). Hiding or disguising the signs of delayed sexual maturation appeared easier in adolescence for the adolescent female interviewees with small immature breasts and child-like bodies, than for the boys who could not hide the absence, or excessively late arrival, of the growth spurt, deeper voice and facial hair.
Thus, many early onset interviewees did not conform to expected social representations of chronological age, including gendered representations, especially at adolescence (Arbeau, Galambos, & Jansson, 2007). For them their 'subjective' age was lower than their chronological age, as has been reported for those with motor disabilities (Galambos, Darrah, & Magill-Evans, 2007; Galambos, MacDonald, Naphtali, Cohen, & de Frias, 2005; Shanahan, Porfeli, Mortimer et al., 2005; Willis, Miller, & Wyn, 2001). This presented an additional challenge to developing a secure positive subjective identity in adolescence.

9.2.6. Summary
Renal replacement therapies were inherently full of uncertainty and interviewees' lives were dominated by events, largely beyond medical or human control. The long-term unsustainability of both dialysis and transplantation meant that interviewees faced changes of modality of RRT throughout their lives. Whilst complex medical histories were more common, as would be expected, in the prepubertal onset group, many later onset interviewees experienced serious problems with dialysis and/or transplant failure, from beginning RRT onwards. Thus their capacity to make their own choices and exert control over their lives was limited by the uncertainties associated with their health; most knew their life expectancy was reduced, and that death was never far away.

The timing of the initial biographical disruption was crucial and the age at which study participants first became ill with ERF had a significant impact on their attainment of markers of adulthood. Qualitative data showed that those who were ill in the earliest years of life suffered disruption at more of the critical times that affect progress from childhood to adulthood, than those with later, postpubertal onset. These critical times were age specific and included beginning school, changing school, examination times, moving on to post 16 education or training, and beginning employment. At any of these times, a change of RRT modality or another serious acute health episode, adversely affected their ability to realise their full potential in adult life.

The age at which participants first became ill was also crucial in understanding what these experiences meant for their developing identity. Most interviewees who were ill very early in their childhood had grown up with the 'illness' identity they had been given by health professionals (Leiter, 2007). Most of the pubertal/postpubertal onset group had, on the other hand, experienced a closer to, what might be called, a 'normal' childhood, and when they became ill, had established more positive emergent adult identities (Arnett, 2000, 2001). While they went on to experience the
same kind of physical trauma to their bodies as the prepubertal group, most were more physically and developmentally similar to their peer group in many respects.

Thus their experiences were closer to those described in the sociology of chronic illness literature in that they suffered a sudden disruption to their normal lives, and associated loss of positive self-identity when they became ill (Aujoulat, Marcolongo, Bonadiman et al., 2008; Bury, 1982; 1991, 2002; Bury & Gabe, 2004; Charmaz, 1983; Williams, 1984).

Most of the challenges that the interviewees faced in entering adulthood with ERF were shared by young adults with other serious chronic illnesses, especially CF, but few researchers have drawn attention to how biological disruption in adolescence was experienced differently to that later in adult life, as reported by Grinyer (2007). However, Grinyer's study did not allow a distinction to be made between pre and postpubertal onset of illness.

9.3. ADULT IDENTITIES, EMBODIMENT AND ERF

Identity development continues into emerging adulthood, but the context in which it occurs changes. After leaving education, adolescents move into a social world where they are often unknown and meeting people for the first time. In such situations, the social representation of chronic illness and social interactions with new adults, become more important for identity development than they were in childhood.

9.3.1. Social invisibility

Pierret (2003 p 15) identified a need to explore the role of the media in diffusing 'values and norms' about the body and health, and by implication illness. ERF is unusual, in that not only is it mainly invisible, and affected individuals are 'discreditable' rather than 'discredited' (Goffman, 1963), but also it is invisible in society as a disease which affects young people. Popular understanding of ERF is largely reliant on the media which offer a simplistic dichotomous representation of RRT as 'medical triumph' versus 'personal tragedy' (Kierans, 2005 p 343). Many participants in the present study were clearly dissatisfied with this, either because it over glamorised transplantation, minimising the reality of life-long dependency on medical technologies and eventual 'transplant failure', or it was over-gloomy and doom-laden about life on dialysis. They saw such portrayals as denying their own experiences, and as threatening their identities as 'normals'.
Study participants said that, outside their immediate family, only a few friends had any real understanding of the meaning of their illness. Interviewees described how friends ‘forgot’ about time-consuming demands of dialysis and its impact on their availability to participate in social life, and the fluid and dietary restrictions of ERF. Similarly, for transplant patients, friends did not remember or understand their fear of common infections and their fear of losing their transplant, nor the reasons for their limited energy and/or limited participation in some sports. There was some evidence to suggest that, as interviewees got older, friends were more understanding if they were well educated and had an understanding of kidney function, or had been exposed to equal opportunities’ policies in employment.

In wider society, social representations exist for more socially visible, but ‘invisible’, diseases like asthma or diabetes, with more adequate social expectations of how sufferers will behave, and the kind of constraints to normal life they might experience. The interviewees found social representations of ERF hardly existed, and described how embarrassing and difficult it was to explain their behaviour in everyday social situations, when faced with incomprehension, and little awareness even of how the kidneys work. The location of the transplanted kidney in the ‘tummy’ was a subject of incredulity, and people’s responses were insensitive, reducing the interviewee to an object of curiosity or pity. However, social visibility does not necessarily offer adequate social representation, as in epilepsy, which is more common, but poorly understood by the public (Scambler & Hopkins, 1986), and, in common with such disease groups (Atkin & Ahmad, 2001; Scambler & Hopkins, 1986), the limited social representation of ERF contributed to making the development of a positive sense of self more problematic.

Lonardi (2007 p 1627) discussed how, if social representations of such diseases are ‘incomplete’, and sometimes developed only within the family, then sufferers find themselves accepted in the family, but at risk of rejection by the wider world. She found that people who talked and were open about their condition, assimilating it into their identity, were the ones who were more successful in overcoming its impact on their lives. However, for most ERF interviewees, openness was problematic, and very few benefited from honesty. In order to launch themselves onto the adult social world and overcome their difficulties, they needed to ‘discredit’ themselves at a point in their life course where peer acceptance was arguably more important than at any other. Many interviewees who were open were discredited and rejected.
Most of the interviewees, irrespective of modality of RRT, stressed how they lived or wanted to live ‘normal lives’, as has been reported in other studies of renal patients (Crowley-Matoka, 2005; Olausson, Utbult, Hansson et al., 2006; Tong, Morton, Howard et al., 2011; Wise, 2002), and in studies of chronic illness in emerging adulthood (Atkin & Ahmad, 2001; Goffman, 1963). In their accounts interviewees ‘talked the talk’ of normality, finding everyday reasons to explain why their looks and/or their behaviour were different from other people’s; a task made easy because ‘stigmata’, such as the ‘moon’ face, dark shadows under the eyes, tiredness, and buying but not finishing drinks, could be easily ‘passed’ as ordinary weight gain, tiredness or lack of thirst.

The assertion of normality was reflected in how most sought friendships within their healthy peer group, and by their general unwillingness to label themselves as ‘disabled’. Few had joined illness-related social groups frequented by adults with chronic diseases (Petersen, 2006; Please, Burrows, Loader, Muncer, & Nettleton, 2000; Sulik, 2009; Ussher, Kirsten, Butow, & Sandoval, 2006) or accessed on-line illness-related support groups; those who had, had ‘helped out’ with IT or used their experience to ‘help’ others. Some of this was about the negative effects of belonging to support groups, as identified by Bury (1991). Where kidney websites were used, it was almost always for ‘information’ and not illness ‘support’, as described by some researchers (Please, Burrows, Loader et al., 2000; Rich, 2006; Sanders & Rogers, 2007). However, normality became harder to sustain as social relationships progressed, as has been found in other studies of ‘invisible’ chronic illnesses (Atkin & Ahmad, 2001; Grinyer, 2007; Leiter, 2007; Lowton, 2004; Sanderson, Calnan, Morris et al., 2011).

In summary, some interviewees, especially those with prepubertal onset, failed to resolve the tensions between their competing sickness and ‘normal’ identities in the wider social world and found themselves ‘unclassified or unclassifiable’ (Navon & Morag, 2004 p 2344). Thus, the social invisibility of ERF in the wider context in which the interviewees were seeking employment and making new social relationships, made achieving these goals more challenging for them than for older adults and those with more common chronic conditions, where social representation of the illness perhaps more closely matched personal experiences.

9.3.2. ERF, embodiment and gender
The role of the physical body was especially salient in ERF, as in many other illnesses (Frank, 2004; Kelly & Field, 1996; Kierans, 2005; Madden & Sim, 2006;
Many who had been ill from an early age, or had complex histories, had accumulated a multiplicity of body scars, as well as having visceral abnormalities. Thus, their bodies were not 'normal' at a time in their lives when they were acutely aware of differences between their own bodies and those of their peers, and of all pervading media representations of young adults, as fit, slim and healthy (Buckingham, 2009; Watson, 1998).

For the transplanted young adults, all signs of ERF were usually hidden from view; for those on dialysis, access points were usually covered by clothes, and little abnormality was immediately visible. All the young adult interviewees had experienced, immediately post-transplant, changes of body shape they perceived as 'gross', and felt stigmatised by obesity, hirsute skin and moon face, which, however short term, were 'abnormal'. Such sudden, extreme yet reversible, body changes appear to be relatively unusual in other chronic illnesses experienced by young adults. Those on HD made no reference to the 'strange' experience of seeing their own blood circulating outside the body (Kierans & Maynooth, 2001), but found their HD access points were 'strange' objects of curiosity to other people, if inadvertently exposed. Those on PD experienced the effect of having huge volumes of dialysis fluid in their abdomen all the time, distending it enormously, and for female interviewees, making them appear pregnant, but again, made no mention of these things. Although these technologies blurred the boundaries between the body and 'other' (Lawton, 1998), in ERF, as in DMD (Gibson, Young, Upshur et al., 2007 p 510), they were taken for granted; the 'techno body', the 'con-corporation of flesh and machine', was their 'lived' body.

As young adults, most interviewees, especially those who were relatively well, appeared to construct their gendered identities as 'normal' men and women, rather than renal patients. The evidence suggests that the males in this study, many of whom were much smaller than normal for their age, had experienced more challenges in conforming to normative male images of strength, power and sporting prowess as children, than the females had experienced in conforming to normative images of femininity, which were less compromised by small height and physical immaturity. Research into young people with asthma and diabetes showed how these illnesses also threatened the gendered role identities of young men more than the gendered identities of young women (Williams, 1998), and this meant that the young men in Williams' study were more likely to minimise the disease and its effects; a finding largely confirmed by the data presented in this study.
In CF, the social meanings of masculinity and femininity favoured survival of males over females (Willis, Miller, & Wyn, 2001), because adherence to treatment regimes threatened female attractiveness and slender body shape, more than the need to be fit affected adherence in young men with CF. These findings were not consistent with the ERF experience in this study, where both genders appeared to be equally concerned about their appearance, and, while more young men talked about sport, there was little difference between the genders in the interviewees' attitudes towards fitness as adults. Equally, there were no observed gender differences in adherence to medical advice or attitudes towards adherence amongst the interviewees. However, in one study, adult males with ERF were reported as being less likely to comply with treatment regimes than females, and females as having lower morbidity and mortality (Rosenberger, Geckova, van Dijk, Nagyova, Roland, van den Heuvel et al., 2005).

Few interviewees expressed concern about the sexual desirability of their bodies, as discussed for women with disabilities (Zitzelsberger, 2005), but their mothers data suggested this was of great importance for both genders. The reproductive body in ERF was affected viscerally, as well as superficially, and from birth and/or puberty onwards, questions of reproductivity, and perceptions of reproductivity, were experienced in gender-specific ways. A review by El-Husseini reported sexual dysfunction in significant proportions of young adults with early onset ERF (El-Husseini, Hassan, Sobh et al., 2009).

For male interviewees with ERF, there was the possibility that treatment, or their underlying disease, meant they were infertile (two knew they were sterile). However, few expressed worries about fertility, and most showed more concern about their future ability to fulfil their gendered role as fathers (Watson, 1998). Females with ERF also feared infertility, but worried more about damage to their own health and transplant, if they went through pregnancy and childbirth, which were both perceived as extremely risky for themselves and the unborn child. Few women on dialysis have given birth, and the birth rate for transplanted females is lower than for the general population (Gill, Zalunardo, Rose et al., 2009). Both the female interviewees with children had experienced difficulties in pregnancy and childbirth such that they would not have another child.

Some ERF interviewees of both genders knew, like those with CF (Lowton, 2004), that they had an inherited/inheritable condition, and knew the likelihood of passing on the disease to their children (Petersen, 2006). There were more of these in the early
onset group. Others had no primary diagnosis, and faced more uncertainty around inheritability. For both groups having a baby was problematic.

Overall, gendered aspects of the embodiment of ERF presented challenges to gendered identities in young adulthood, including reproductivity, especially those with early onset, that were perhaps more limiting than those presented by many other invisible chronic diseases of childhood.

9.3.3. Stigma, age of onset and passing for normal as adults
Concepts such as presentation of self and stigma (Goffman, 1959, 1963) remain important in exploring emerging adulthood with ERF and other chronic diseases of young adulthood. Moreover the distinction between perceived (or felt) and enacted stigma (Scambler, 2004; Scambler & Hopkins, 1986), and feelings of shame with respect to underachievement (Clark, 1987), are especially salient for an invisible disease at this life stage.

Issues of adult identity and self came to the fore in emerging adulthood, as interviewees increasingly experienced social pressure to account for themselves outside the familiar environments of home and school. For prepubertal onset interviewees, by the time they left education many had accumulated a history of stigmatisation, discrimination and rejection, which, in turn, had informed their views of how they might be regarded in the wider social world.

Crucially, many of the early onset interviewees experienced feeling increasingly different from their healthy peers and disadvantaged, if not actively discriminated against and rejected, in seeking a job or an intimate partner, in a competitive 'market', where positive self presentation was key, and most of their peers were well, and apparently 'normal'. Unemployment itself was also potentially stigmatising, and several male interviewees were ashamed of being unemployed and failing to make 'proper' use of their time, in the same way as young men with DMD (Gibson, Zitzelsberger, & McKeever, 2009).

In contrast, the late onset interviewees suddenly became seriously ill at a time which posed an immediate threat to their more established adult social identities as 'normal' (Arnett, 2001; Atkin & Ahmad, 2001; Grinyer, 2007). When they met other patients on the adult hospital ward or at clinic, they were exposed to graphic evidence of how ERF would affect their future lives, then feared negative perceptions of themselves as potential friends and colleagues, and possible rejection. These experiences of the
late onset interviewees were more similar to experiences of older adults diagnosed with chronic illness (Bury, 1982, 2002; Charmaz, 1983, 2000; Corbin & Strauss, 1987; Kelly & Field, 1996; Williams, 1984; Williams, 2000b). However, they were experienced differently because they were at the threshold of adult life, and still seeking a partner, employment and/or independent living (or had achieved these goals of adult life later than their peers), as reported for other young adults with chronic illness (Atkin & Ahmad, 2001; Grinyer, 2007).

Most mid life or older adults who become chronically ill already have, or have had, a job, and most have or have had a partner. Many have been able to reconcile their new life and identity with their old, through self reflection and narrative reconstruction (Sanderson, Calnan, Morris et al., 2011; Williams, 1984; Williams, 2000b), arguably more easily than emerging young adults. In addition, many people at a later stage in the life course find there is less stigma and shame attached to being chronically ill, because to some extent, this is considered ‘normal’, as levels of chronic illness increase with increasing age (Hockey & James, 1993; Pound, Gompertz, & Ebrahim, 1998; Rozario & Derienzis, 2009). Equally, as individuals approach normal retirement age, there is less stigma attached to being unemployed. These differences led Grinyer (2007) to argue that age and life stage ameliorate or exacerbate the experience of chronic illness, and in young adulthood, being young exacerbates more than ameliorates its effect.

**9.3.4. Disclosure to friends and potential partners**

Stigma and shame in ERF were particularly associated with the imperfect physical body. While most interviewees said that they had ‘no problem’ with exposing their numerous, some grotesque, body scars, their survey responses revealed that almost half felt upset about them. For all of them, any visible and significant differences from a ‘normal’ appearance and presence of dialysis access appurtenances had to be managed to avoid discreditation (Goffman, 1963). Research on slightly older adults with CF (mean age 30) (Lowton, 2004) described the risks of adverse consequences following ‘discovery’ of illness status by friends, as medium, but the risk of accidental disclosure in ERF was less than in CF, where inability to control the characteristic cough could lead to unplanned disclosure (Lowton, 2004).

The kind of ‘management’ needed in ERF, however, limited everyday social participation. Simple adult social activities such as sharing meals out, having a coffee or a drink were restricted by diet or fluid constraints. Females who were very small, found age-appropriate clothes hard to find, making it embarrassing to go shopping.
with friends. Age appropriate behaviour on holiday brought a range of challenges from the exposure of scars and/or tubes and risks of swimming, to getting skin cancer, and many interviewees avoided social situations that meant taking clothes off. Overall, such behavioural differences added to feelings of being different from their peers, and also to the risks of accidental disclosure.

Several ERF interviewees said they never told anyone about their health status, and many felt unable to tell anyone they met, for fear of rejection. Others had been rejected by friends when they became ill. Moreover, more interviewees found it difficult to talk about themselves than might be expected from their survey responses, where only a quarter of them said ERF made it difficult. Some interviewees on dialysis thought it would be easier to talk about ERF when/if they got a/another transplant, because they could present themselves as ‘healthy’. However, failure to share and exchange personal and intimate information constrained their friendships.

Some interviewees found that disclosure made life easier for them when they started a new life, for example at university, confirming Lonardi’s (2007) observations about the benefits of openness. Evidence also suggested that ‘coming out’ was easier as they got older, and, easier if they got to know someone first. However, overall, experiences of openness were mixed and there was no ‘ideal time or age’ for self-disclosure.

Almost all those with ERF were keen to find a partner and have children. However, with limited social networks, meeting potential partners was difficult. Several found that casual meetings in social venues such as bars did not lead to finding a partner and talked about the importance of making close friendships, and building up love and trust, before physical intimacy. Disclosure of illness status to potential intimate partners presented new challenges, and had presented the highest risk of personal discreditation for those with CF (Lowton, 2004). Some ERF interviewees (younger) worried about whether they would be able to find a partner at all, and what, when and how to disclose to potential partners.

Most interviewees with ERF found it difficult to talk about their experience of intimate relationships, and their mothers provided supplementary data, describing their anxieties about displaying their physical bodies. Several interviewees described being rejected by potential partners after disclosure, but only one male talked explicitly about an intimate sexual experience, and subsequent rejection. Few interviewees mentioned ‘partial’ disclosure, used by those with CF and epilepsy
(Lowton, 2004; Scambler & Hopkins, 1986), although one let something 'leak' out. Female interviewees talked more openly than the males about rejection, and felt that it was either their present (more than their future) health and/or issues about having children, that had led to the breakdown of previous relationships. Several of both genders having experienced rejection, had temporarily abandoned any thoughts of intimate relationships. Others expressed worries about disclosing the inheritability of their condition, the burden of future care they might place on a future partner, and longevity. These experiences were mostly shared by the older adults with CF (Lowton, 2004 p 177-178).

Ultimately, many, even with successful transplants, found disclosure to peers and potential partners too difficult, and continued to 'pass for normal', not disclosing their ill health at all. At the same time, they were aware that they were in increasing danger of being exposed as 'fraudulent' (Lowton, 2004), and losing their social identity as 'normal' individuals.

9.3.5. Disclosure in employment

Those with chronic illness or disability often face difficulties in finding employment (Blum, White, & Gallay, 2005; Ferrier & Lavis, 2003; Green, Todd, & Pevalin, 2007; van Campen & Cardol, 2009; van der Wel, 2011; White & Gallay, 2005), especially if their educational resources are few. For adults with CF, disclosure in employment situations carried a high risk of adverse consequences (Lowton, 2004 p 176). The ERF interviewees feared discrimination and rejection, and whether they were well and looked normal, had previous work experience, or had knowledge about/personal experience of discrimination, were key determinants of their employment disclosure behaviour. Seeking employment offered them three opportunities to disclose their illness status: when applying, at interview or when already in work. Some interviewees had experienced discrimination in employment at all three stages, as had adults and young people with other chronic illnesses (Atkin & Ahmad, 2001 p 623; Lowton, 2004; Ostberg & Modin, 2008; Rao, Angell, Lam, & Corrigan, 2008; Scambler & Hopkins, 1986).

Many interviewees with ERF described the tactics they used to avoid disclosure and rejection in employment, which meant, for the most part, avoiding or delaying disclosure to employers. They obtained temporary work, short term contract work, became self-employed, or worked in family businesses, where they did not need to disclose their health status at all, or waited until they were established as employees. On the other hand, for those who could not find work, disclosure offered opportunities
to seek support from Job Centres, or apply for 'access to work' schemes restricted to people who were registered as disabled, but these were used mostly by male interviewees. However, most interviewees had ambiguous feelings about identifying themselves as 'disabled' as they perceived it as stigmatising (Galvin, 2005; Phelan, Link, & Dovidio, 2008; Susman, 1994). Nevertheless, more interviewees reported being registered 'disabled' than saw themselves as 'disabled', which suggested it was advantageous for some, if not to get work, then to claim benefits to support the additional financial burden of being ill.

Overall, there were many very difficult disclosure issues to address for those with ERF in employment and peer relationships, and some which arose only in the context of finding an intimate partner. Issues related to the embodiment of ERF made talking or even thinking about sexual intimacy, and/or having children, especially difficult for most. Such difficulties were experienced by all those with ERF, but more intensely by those on dialysis, and those in the prepubertal onset group, perhaps because of their earlier and longer history of discrimination. For these groups, the differences between their physical bodies and those of their peers were greater.

### 9.4. SOCIAL MARGINALISATION

Adult transplant patients have been described as carving out 'an existence in the persistently liminal spaces ... between the roles of 'sick' and 'healthy', dependent patient and fully contributing family member' (Crowley-Matoka, 2005 p 830). Similar marginalisation, and/or social isolation, has been reported in studies of emerging young adults with other chronic illnesses and disabilities (Atkin & Ahmad, 2001; Gibson, Young, Upshur et al., 2007; Grinyer, 2007; McDonagh & Kelly, 2007; McDonagh, Southwood, & Ryder, 2000; Stam, Hartman, Deurloo et al., 2006; White & Gallay, 2005). Crucially none of these studies draws attention to how early childhood presentation of serious illness affects becoming a 'fully contributing family member', compared with later presentation in adolescence.

### 9.4.1. Underachievement of measurable goals of adulthood

Illness in childhood has been linked to immediate, and long-term, higher unemployment rates in early adulthood, for a range of chronic illnesses (Lindeboom, Nozal, & Van Ver Klaaw, 2006; McDonagh, Southwood, & Ryder, 2000; NCCSDO, 2002; van der Wel, 2011), and for those with disabilities (Hills, Brewer, Jenkins et al., 2010; Janus, 2009), and employment destinations for young adults remain highly dependent on educational attainment level (Brooks, 2006; Hills, Brewer, Jenkins et
al., 2010; Lindeboom, Nozal, & Van Ver Klaaw, 2006; ONS, 2009; Osgood, Ruth, Eccles et al., 2005; van der Wel, 2011; van der Wel, Dahl, & Thiel, 2011). In particular, young adults with paediatric presentation of ERF achieve fewer measurable markers of adulthood than their peers (Bartosh, LeVerson, Robillard et al., 2003; Broyer, Le Bihan, Charbit et al., 2004; Groothoff, Cransberg, Offringa et al., 2004; Groothof, Grootenhuis, Offringa et al., 2005; Offna, Latta, Hoyer et at., 1999).

Survey data from this study confirmed these data but more importantly showed that those with prepubertal presentation of ERF achieved fewer adult markers than their post-pubertal onset peers, in education, employment and independent accommodation. The qualitative data showed how prepubertal onset interviewees differed from those with postpubertal onset in that more of them underachieved or experienced delayed achievement educationally, and several were still trying to 'pass' their GSCEs when interviewed. This delayed their progress into full time employment. Most of the later onset group had achieved the kind of GCSE results they had expected, although at the next stages, several suffered serious setbacks to their progress into adulthood.

For the older interviewees, unemployment, underemployment and delayed employment as adults both reduced the size and diversity of their social networks, and meant many were slow to achieve, or had not achieved, financial independence, independent living accommodation and intimate partners. But this effect was greater for some of the earliest onset group, those who had been ill in their primary school years, especially those least able to 'catch up' educationally. Thus prepubertal onset interviewees, like others with childhood chronic illness and disability, were more likely to face a life time of underachievement, as has been demonstrated in quantitative studies of disadvantaged children and young people (Schoon, Bynner, Joshi, Parsons, Wiggins, & Sacker, 2002; Thomson, Bell, Holland et al., 2002; Wagner & Blackorby, 1996).

Overall, employment outcomes in this study (Table 31) were comparable with national statistics (ONS, 2010), which showed that 56% of all adults with disabilities were restricted in the type or amount of paid work they did (more than double that for adults without impairments).

9.4.2. Social isolation

About a quarter of study participants reported that ERF made making friends and keeping friends harder. Difficulties in participating in the same activities as their peers
increased as study participants got older, and interview data showed that some jeopardized their treatment regimes to accommodate their social lives, as have young adults with different chronic illnesses (Atkin & Ahmad, 2000; Badian, 2006; Balfe, 2007). About a fifth reported feeling lonely or isolated, and although most placed great importance on having friends, only half felt like seeing them frequently, and few talked a lot to their friends, even their families, about how they were feeling.

Interview data suggested that some prepubertal onset interviewees had fewer friends and lived more isolated lives than the postpubertal group. Many had been brought up in single parent families, usually by their mothers, who found it hard to continue working, and with fathers who did not play a large role in their lives. These factors contributed to early marginalisation from mainstream social life for those with prepubertal onset of ERF. Many in the early onset group said they had very few friends who understood, and it is likely that their remaining childhood friends had been too young to understand ERF at the time, and had since ‘forgotten’ how it had been. Only two or three interviewees were in touch with patients they had known in the paediatric unit. In contrast, most of the older onset group, retained their friends when they became ill, although not all. Many also lived in an environment where everyone knew what had happened to them and, friends, being older, had more understanding.

Social isolation was compounded for the interviewees by the culture of adult renal services, where they rarely saw another young patient, the same patients or the same doctor regularly or frequently (McDonagh, Southwood, & Ryder, 2000; Shaw, Southwood, & McDonagh, 2004b). Those on dialysis had little in common with older people on the dialysis ward, many of whom were terminally ill with little hope, and made depressing company. As a result, few mentioned friends they had made on their dialysis shift, other than interviewees who had no ‘normal’ life away from the hospital. Moreover, adult hospital staff had little understanding of the social needs of young adults, who were, for them, a fairly new ‘client group’ (BAPN, 2003; McDonagh & Kelly, 2007; Watson, 2005, 2006). In addition, choosing not to seek support from the kind of illness support groups used by others with chronic illness (Locock & Brown, 2010; Ussher, Kirsten, Butow et al., 2006) possibly compounded feelings of isolation.

In addition, several interviewees, especially those with few social resources, were marginalised by unemployment, and, finding no opportunities to work, appeared resigned to living at home with their families, often just their mothers. In this they
became similar to the young men with DMD (Gibson, Young, Upshur et al., 2007) whose social marginalisation meant some failed to engage in social life beyond the family at all. Geographical isolation in areas where community networks no longer provided the support they used to do (Pleace, Burrows, Loader et al., 2000; Veenstra, 2005; Veenstra, Luginaah, Wakefield, Birch, Eyles, & Elliott, 2005), further isolated several who could not drive.

Finally, a disproportionately large group of older male interviewees lived alone, which is perhaps indicative of the isolating effect of chronic illness. It was a constrained 'high risk' choice for those on dialysis, especially if their lifestyle involved elements of non-adherence to treatment/advice. Female interviewees, who had left home, were all sharing accommodation with a partner or friends.

Personal attributes and social structures played a role in marginalising those with ERF, as they do for all emerging young adults, but more so for those ill from early childhood. Atkin and Ahmed (2001) found that threats to successful transition into adulthood in SCD came not only from the disorders themselves, but were socially imposed and depended on individual personal strengths and attributes, and social and material resources. Disability, race, culture, and social resources were all salient (Anderson, Bechhofer, McCrone et al., 2005; Atkin & Ahmad, 2001; Brannen & Nilsen, 2007; Brannen & Nilsen, 2002; Bynner, 2005; Cassidy, O'Connor, & Dorrer, 2006; Cieslik & Simpson, 2006; Holland & Thomson, 2009; te Reile, 2004; Thomson, Henderson, & Holland, 2003).

Depression has been widely reported in young transplant patients (Berney-Martinet, Key, Bell et al., 2009; Bunzel, 2000; Dobbels, Decorte, Roskams et al., 2009; Penkower, A., Ellis, Sereika, Kitutu, & Shapiro, 2003; Rubik, Grenda, Jakubowska-Winecka, & Dabrowska, 2000). About a fifth of survey respondents reported feeling lonely and isolated, and the same proportion, depressed. Data from about a quarter of interviewees suggested elements of loneliness and depression in spite of general positive presentations of self. There are clear associations between chronic illness and mental ill health (Blaxter, 2004 (2); Herzlich, 2004; Williams, 2000b), but the mechanisms by which this operates are varied. It is possible that failure to attain expected markers of adulthood could be playing an important role here (Mossakowski, 2011).

The qualitative data suggested that social isolation was possibly related to unresolved social identity issues and difficulties in disclosure, and might have
contributed to depression in emerging adulthood for those with ERF. Several prepubertal onset interviewees described having counselling in childhood/adolescence, but only two in adulthood. Others had vehemently rejected counselling opportunities in childhood. Those who had had counselling had found it easier to talk to the interviewer about themselves, and had developed manageable stories to tell. This would support Lonardi’s findings discussed earlier (Lonardi, 2007).

In summary, marginalisation was clearly multifaceted. Underachievement in education, employment and independence meant that more early onset interviewees had fallen behind their peers in the transition to adulthood. The social isolation some experienced was in part related to this, their early childhood, and to ERF itself: its side effects, and the time it took away from normal social life. In addition, some had become depressed. Most of these experiences were shared by the later onset group, but less acutely, and overall, while some interviewees had made a relatively successful transition, many more had difficulties, and several were seriously marginalised.

9.5. ROLE OF SOCIAL RESOURCES

Over more than 40 years a large body of literature has examined structural determinants of health, but more work is needed on the relationships between social structures, social resources and subjectivity in chronic illness (Bury, 1982; Pierret, 2003; Radley & Green, 1987). In this study, a dominant strand in the interview data related to the way in which access to social capital had shaped the early lives of the interviewees and their trajectories into adulthood. This section discusses how social capital was used by the parents of the interviewees with ERF in childhood as ‘social support’ (Blum, 1995; Harley, 2001; Schoeni & Ross, 2005).

Whilst structural factors and social inequalities shape the experience of adults throughout their life course (Blaxter, 2004 (1); Hills, Brewer, Jenkins et al., 2010; Marmot, 2010), they are demonstrably critical at the beginning (Brannen & Nilsen, 2005; Evans, 2002; Holland & Thomson, 2009; OECD, 2009; Ostberg & Modin, 2008; Sacker, Schoon, & Bartley, 2002; Thomson, Henderson, & Holland, 2003), and important in assisting those with chronic illness to achieve success in emerging adulthood. Every family comes to the experience of having a child with chronic illness with different levels of social capital (Bagnall, Longhurst, & Savage, 2003), and the families of those with childhood ERF drew on a variety of social resources in their endeavours to ‘sustain’ normal family life.
Parents of children with chronic illness need to be in optimum health themselves, but biographical disruption of the kind they themselves experience has been recognised in the aetiology of mental health problems and some chronic illnesses (Harpham, Grant, & Rodriguez, 2004; Pilgrim, Rogers, & Bentall, 2009; Williams, 2000b; Ziersch, Baum, MacDougall, & Putland, 2005). All the families affected by ERF faced continuous psychological stresses and anxieties that were hard to alleviate (Anthony, Hebert, Todd et al., 2009; Simons, Ingerski, & Janicke, 2007), and even where sufficient social resources were available, these stresses remained, adversely affecting the health of several of the interviewees’ parents.

Several ERF interviewees lived with parents whose physical and/or mental health had been affected by the accumulated effects of ERF in the family. Some parents were depressed, some had high blood pressure, diabetes and/or were obese. Some (ten) parents had been kidney donors, and not all had fully recovered; others were being ‘worked up’ for donation. Only healthy, fit, mentally well parents were considered ‘suitable’ donors, and work up involved major stress as well as nephrectomy (Burroughs, Waterman, & Hong, 2003; Crouch & Elliott, 1999; Gordon, 2001). If unsuitable, because of previously unknown health problems, this added extra anxieties.

### 9.5.1. Family breakdown

Where a chronic illness like major organ failure begins at birth, or in the years before puberty, the affected families are for the most part devastated (Dobbels, 2007). Paediatric presentation of serious disease means that affected children are often treated in specialist hospitals. Where the illness is particularly rare, and treatment technology intensive, as in organ failure, specialist paediatric units are few, and families are faced with the disruption and expense of long journeys, and hospital stays, far from their home. In ERF, there were no alternatives to immediate hospitalisation and the treatment regimes imposed immediately were highly intrusive, in all senses. Thus, families of the children experienced immediate demands on their social capital (Parcel & Menaghan, 1993; Wright, Cullen, & Miller, 2001). Extra financial capital was needed to meet the costs of travel to a (usually) distant renal paediatric unit and overnight accommodation, usually for their mothers.

Parental relationships needed to be strong, if the family was not going to be overwhelmed by meeting the needs of the sick child, alongside the demands of managing the home, employment and the rest of the family (Anthony, Hebert, Todd et al., 2009; Young, Mintzer, Seacord, Cataneda, Mesrkhani, & Stuber, 2003). It was
especially difficult where the interviewee was a baby or small child, and their mothers 'lived in hospital', often for several months with only weekend breaks (Hickey, 1972). Most families turned to extended family or friends nearby for initial support.

Twelve of the interviewees, almost all prepubertal onset, were brought up in single parent families, after their fathers (11/12) left home soon after RRT began. Families across all social classes were affected. Similar difficulties in family relationships and family breakdown have been reported in families with young children with a range of serious chronic diseases or disabilities, including ERF, affecting both family and sibling relationships (Anthony, Hebert, Todd et al., 2009; Cimete, 2002; Foster, Eiser, Oades et al., 2001; Hickey, 1972; Manificat, Dazord, Cochat et al., 2003; Shandra, Hogan, & Spearin, 2008; Simons, Ingerski, & Janicke, 2007; Soliday, Kool, & Lande, 2000; Tong, Lowe, Sainsbury, & Craig, 2008; Yoshino, Toshono, Kusano et al., 2007). Family breakdown had far-reaching consequences, as it meant a loss of earned income, financial hardship, less social support for parent and siblings, and fewer gender-appropriate role models for the child/ren; effects that are well known (Hills, Brewer, Jenkins et al., 2010 p80, p181; SJPG, 2006; Valentine, Skelton, & Butler, 2002).

9.5.2. Social and family capital in childhood

Chronic illness places a financial burden on families across all age groups, including reduction or loss of earnings, so that any socioeconomic effects of wider financial inequalities in society on children's welfare and development (Currie, Molcho, Boyce, Holstein, Torsheim, & Richter, 2008; Macintyre, 1997; Marmot, 2010; Williams, 2003a) are exacerbated by illness in a child. Early quantitative studies of normal and disabled children in the US and elsewhere (Sacker, Schoon, & Bartley, 2002; Schoeni & Ross, 2005; Wagner & Blackorby, 1996) show that higher income and socioeconomic status help children and young adults to continue their education and establish independence.

In paediatric ERF, there were continuing costs over time: special diets, dedicated accommodation for home dialysis, and extra help with education. Interview data showed that financially well resourced families were able to cushion the impact of extra expenses better than those less well-resourced. Their children were helped through payment of tuition fees, and later, board and lodgings where necessary/desirable, after the normal school leaving age. Other families struggled in relative poverty, especially where they were single parents, managing on benefit income, or they had to give up employment or reduce their working hours. If their
children did less well than expected at school, they had fewer financial resources to fund continuing education.

Social class is closely linked to educational aspirations and success, and to feelings of confidence and competence (Reay, 2005). Although some researchers found that the advantages derived from being middle class did not operate for parents of children with disabilities (Wells, Sandefur, & Hogan, 2004), other researchers reported that the social and cultural capital associated with being middle class are advantageous in adversity (Blaxter, 2000; Li & Pickles, 2005; McKeever & Miller, 2004).

The evidence in this study shows cultural capital was used to positive effect in prepubertal ERF, as middle class interviewees particularly benefited from having parents who were sufficiently educated and articulate to contribute effectively to health and education-related decisions affecting their children. They addressed health and education professionals, especially hospital consultants, as equals, and in demonstrably comparable professional language. Objectivity lent strength to these parents' arguments, and they were able to rearrange clinic appointments and non-urgent surgery to more convenient times. In education, they acted to minimise the disruption to their child's education by being able to assess the suitability and effectiveness of hospital, and LEA alternative educational provision, in meeting their children's educational and social needs. However, resisting institutional structures/practices was not exclusively a middle class practice, and notably, one working class mother 'took on' the statutory authorities (education and social services) successfully.

The data showed that use of cultural capital in this way was usually beneficial to the interviewees, but, possibly because medical uncertainties have lowered levels of trust in medicine and doctors (Fox, 1980; Giddens, 1991), two middle class families refused dialysis and turned to alternative medicine. Their adolescent sons became very ill as a result.

More generally, the data showed that somewhat patronising medical attitudes to what doctors saw as over-anxious mothers and families existed irrespective of cultural capital, but cultural capital made a difference to the confidence of the family in dealing with this, and challenging perceived medical wisdom/knowledge. There was also evidence that this cultural capital was transmitted to their children, some of whom adopted confident approaches to negotiation with health professionals from an
early age. Families with less cultural capital had to fight harder to ensure that professionals were listening to them, and for their concerns to be recognised.

Many families affected by ERF drew heavily on their social networks for support, especially in the first year/s after diagnosis. These offered social advantages to all families, but operated differently across communities and social classes (Giordano & Lindstrom, 2010; Kanaiaupuni, Donato, Thompson-Colon, & Stainback, 2005; Rose, 2000; Veenstra, Luginaah, Wakefield et al., 2005). For example, Bagnall et al (2003) suggested that the greater civic engagement of socially mobile middle class parents meant their children 'got ahead' educationally, in comparison with the children of less socially mobile working class parents, with networks based on kith and kin. However, middle class mothers of children with ERF felt they were expected to cope alone, and not draw on friends excessively for support; subtle social pressure was exerted on them to prevent their child's illness from becoming too dominant in everyday social discourse.

The findings in this study, especially the responses of the prepubertal onset families to diagnosis of ERF, suggested that social network capital based on proximity was initially most important in accessing social support. Evidence showed how local extended family support contributed to the emotional health of the whole family, and even family 'survival' in one or two families, as has been shown for disadvantaged mothers with young children (Kanaiaupuni, Donato, Thompson-Colon et al., 2005). However, social networks are maintained by reciprocity, and some mothers reported difficulty in finding time to invest in their own social friendships, as has been reported by Marmot (2010). For many prepubertal ERF families, marital breakdown meant renewal and regeneration of social network capital was difficult for the single parents, whose social networks had been reduced, not only by time, but by being out of employment themselves and without an employed partner. Similarly, others have reported that social networks for families of children with disabilities are smaller and denser than those of unaffected families (Kazak, 1987; Kazak & Nachman, 1991; Kazak & Wilcox, 1984).

Cultural networks, and associated strong religious and cultural practices, proved particularly important for interviewees from ethnic minority communities, as they are for other disadvantaged youth (Cassidy, O'Connor, & Dorrer, 2006; Chattoo, Atkin, & McNeish, 2004). However, it has been argued that networks based on ethnic minority communities can disadvantage members with ERF by isolating them from the 'general population' of ERF patients (Browne, 2011); this was not observed.
Overall, social resources were vitally important in managing early onset of ERF in a child of the family. Adequate financial and social network capital were essential in the first few days and months as most families struggled with the illness, the diagnosis and the disruption in caused, and lack of social resources contributed to relationships' difficulties. Social resources, including cultural resources, continued to be important throughout the interviewees' childhoods and were drawn on in different ways as the interviewee grew older.

9.5.3. Social and family capital in emerging adulthood

Social resources played a vital role in the lives of the interviewees with ERF in emerging adulthood. In this section, how family social capital was deployed to support transition into employment and adult social life is discussed.

Overall, the pathways of the interviewees into employment were not very different from those of many emerging adults in the 21st century, as more defer entry into full time employment (Brannen & Nilsen, 2002; SIRC, 2008). In ERF, trajectories into employment varied, few could be regarded as planned; most were unplanned or constrained, and some, where health continually interfered, chaotic (Ford, Rugg, & Burrows, 2002). Both educational delay or underachievement and health, constrained development of interviewees' own social capital.

All the families used their own social resources, including themselves as role models to support their children into employment. Some families employed their own child directly, or provided opportunities through their social networks for employment or work experience, or offered advice. Health made a difference as it did for other young adults with invisible, but physically limiting illnesses (Anderson, Flume, Hardy, & Gray, 2002; Atkin & Ahmad, 2001), and it was harder for interviewees in 'poor' health to find work independently. For them, parental social resources assumed more salience as sources of knowledge about self employment, professional routes into part time work, informed advice about what was practical and sustainable, given health constraints. As in adolescence, financial capital was important, where available, to fund further training.

More of the interviewees from working class families had reached 16 without the requisite 5 'passes' at GCSE (including English and Maths), and several, insufficiently well-qualified to undertake administrative or skilled work, were unable, because of health constraints, to sustain manual or unskilled work. Working class families were less able to provide financial resources to support continuing education.
or employment training, especially if they were lone parents, and for these interviewees, fewer social resources and lower academic achievement combined to reduce their employment opportunities, and more of them were unemployed.

Most middle class interviewees achieved high levels of educational attainment (generally A level or degree) as might be expected (Bagnall, Longhurst, & Savage, 2003; Coleman, 1988; Hills, Brewer, Jenkins et al., 2010). Moreover, their own resources and greater family resources meant they were more likely to find employment, find congenial employment that they were physically capable of sustaining, and change employment where their health demanded a change. Where they were less well, parental resources funded higher educational studies.

Financial capital, friends, and/or a partner were needed for interviewees to establish themselves in independent accommodation. However, for all, leaving home was constrained by health. Some had care needs, similar to some young adults with disabilities (Leiter & Waugh, 2009), and, for example, dependency on a home dialysis machine made interviewees very vulnerable to machine malfunction, so that all those on home dialysis were constrained to live with either a partner or a parent. Fifteen interviewees lived independently of their birth families, and all had met their partners while successfully transplanted.

For interviewees with limited social networks, relative social isolation made it difficult to find a friend or partner to share accommodation. The findings suggested that the female interviewees were more able than males to meet a partner and move away from home through the extended social networks of family and family friends. These were mainly religious networks, or the kind of local community networks that used to be characteristic of village life. Male interviewees faced more difficulties in finding friends and partners, probably because they were more socially isolated and tended to see friends as less important than the females; and for some, the stigma of unemployment had an effect. More appeared to have turned to virtual social networks for friendship and support; three males, but no females, found partners via virtual social networks, two more males had tried internet dating, but without success. Six interviewees, all men, lived alone (all transplanted or on hospital dialysis).

9.5.4. Summary

Social and family resources were used differently in childhood, adolescence and emerging adulthood. As interviewees grew older, their own social resources played an increasing role, but family resources remained more salient for most. The
evidence makes clear that the lived experience of the interviewees in emerging adulthood was socially structured and their transition trajectories into adulthood constrained. While the response of many was to adapt to ill health and they appeared flexible (Brannen & Nilsen, 2002), their choices were constrained, and concepts of individualism and choice appeared less relevant (Beck, 1992; Giddens, 1991). Overall, socioeconomic circumstances made a difference and social disadvantage had a cumulative effect (Schoon, Bynner, Joshi et al., 2002; Schoon & Parsons, 2002; Schoon, Wiggins, Bynner et al., 2002), suggesting that the future lives of the interviewees will be socially structured and experienced in similar ways to those reported in early work by Gerhardt (1990 a; 1991).

This finding supports previous qualitative work with disadvantaged young adults in transition, which has demonstrated how far these young people's lives are still largely shaped and constrained by structural inequalities (Evans, 2002; Holland & Thomson, 2009; Thomson, Henderson, & Holland, 2003). Furthermore, the evidence suggests that socioeconomic disadvantage is as influential in determining both the trajectory and adult destinations of emerging adults with chronic illness, as ill health itself; unless the latter makes participation in adult social life completely unattainable.

9.6. CONCLUSIONS

The thesis has focused on how far the lived experience of early childhood ERF affects emerging adulthood, and how far it is similar to, or different from, the lived experience of ERF diagnosed after puberty, and from other chronic illnesses affecting young adults at this stage in the life course. Emerging adulthood is a period of change as young people make the transition from childhood into independent adult life. The trajectory has become less linear, more fragmented and more prolonged over the last 30 years, than it used to be for all young adults.

ERF is characterised by uncertainty and by social invisibility in the early lifecourse, and those affected face a lifetime of chronic illness and shortened life expectancy. They might expect a longer life than those with CF or males with DMD, but, in common with most serious conditions, longevity and survival in ERF depend on following medical advice and treatment regimes. Treatment technologies offer imperfect 'replacement' of healthy organs, and those with ERF are likely to be 'shunted' between transplantation and dialysis, and between dialysis modalities (HD and PD) several times in their lives. Although some with CF, heart disease, liver failure or diabetes also face eventual transplantation, organ failure usually means
death or another transplant, whereas in ERF, there is a viable medium term alternative, dialysis.

Personal agency is limited for all young adults with chronic illness and disabilities, often in ways that are disease specific, and which depend on treatment regimes, physical and mental health, as well as social factors. Ill health impacts on freedom to makes choices about pathways to independence, constrains social participation with peers, age-related experimentation with life style and risk, education and employment opportunities. Prioritising independence, agency and social relationships with peers over health and adherence to treatment, has been shown to have an adverse affect on health (Balfe, 2007; Laederach-Hofmann & Bunzel, 2000; Rapisarda & Tarantino, 2004; Rianthavorn, Ettenger, Malekzadeh et al., 2004; While & Mullen, 2003; Willis, Miller, & Wyn, 2001).

Almost all the interviewees experienced structurally determined boundaries (Evans, 2002) to their choices about their future life course, more than are suggested in individualisation theorists of the 1990s (Beck, 1992; Giddens, 1991). In common with all disadvantaged and marginalised young adults, their transition into adulthood was shaped by the social resources available to them and their families (Brannen & Nilsen, 2002; Ford, Rugg, & Burrows, 2002), as well as the chronic disease itself. ERF exacerbated initial social disadvantage, so that interviewees with ERF and few social resources (family and individual) became increasingly disadvantaged compared to those with more social resources, who used these to mitigate its effect.

Chronic disease is stigmatising, and development of a secure positive identity is known to be problematic at all ages, but it appears to be more problematic in emerging adulthood than in mid life and older adulthood, where illness is more common as people age, and moreover, often anticipated. Chronic illness early in the life course makes disclosure particularly difficult in emerging adulthood, and failure to disclose illness status affects social relationships and social participation over time, so that transition into employment, independence and intimate partnerships becomes increasingly adversely affected.

Quantitative data presented in this thesis confirmed existing data on adult outcomes for paediatric ERF patients (Bartosh, Leversen, Robillard et al., 2003; Broyer, Le Bihan, Charbit et al., 2004; Groothoff, Cransberg, Offringa et al., 2004; Groothoff, Grootenhuis, Offringa et al., 2005; Offna, Latta, Hoyer et al., 1999). In addition, they showed that survey respondents aged 16-30 who presented with ERF under 16, were
statistically less likely to be successful in educational attainment, employment and living independently, than those 16 or over, at first presentation. Psychosocial markers of social relationships in adult life showed tentative associations in the same direction, but it was the qualitative data that showed that puberty was critical, and that the lived experience of those who had been ill before puberty differed from that of those who were ill during or after puberty.

Young adults' own accounts of living with ERF demonstrated that differences in education and employment could be explained, in part, by the greater cumulative impact of ERF at critical moments in the development of the prepubertal onset group, leading to underachievement or delayed educational achievement, and limitations on employment choices. These had a negative effect on identity development. Moreover, delays in physical, emotional and sexual maturation at puberty affected early identity development, with far-reaching consequences into adulthood. Critical moments existed for the older onset group too, but they were less numerous, and for most, the consequences were less serious. For them, the later commencement of RRT meant that their emergent adult identities as 'normal' young men and women, were relatively more secure and less adversely affected.

A secure positive adult identity appeared crucially important for living independently and forming adult relationships, but interviewees' emergent identities were threatened by the need to disclose their illness status. Disclosure in new social situations, especially in employment and intimate relationships, was challenging, particularly for those with prepubertal onset, and made more difficult by the social and physical invisibility of ERF. This invisibility meant that 'passing for normal' was usually successful, but left interviewees at risk of discreditation by accidental disclosure. This was also the case for young adults with other invisible, but socially more visible, diseases such as asthma, diabetes and CF.

However, the embodiment of ERF, and the embodied effects of RRT, some reversible, some visible but hidden from view, and some visceral, made disclosure and exposure of the physical body especially difficult, in comparison with asthma or diabetes. The body in ERF was subjected to gross changes in size and appearance, and its surface heavily scarred with 'relics' of past surgery, moreover some interviewees' bodies had physical 'intrusions' such as catheters. Visceral abnormalities meant those with ERF had legitimate concerns about fertility and inheritability as do those with CF (Lowton, 2004) making any discussions about partnering and children especially difficult. Gender differences existed, such that
prepubertal onset more seriously affected gendered social roles and social participation of males in transition and adulthood, but reproductivity issues were more salient for adult females than males. Several young men but no young women lived alone.

Overall, interviewees' experience of transition into adult life was shaped by the age at which they first started RRT, the extent and timing of ensuing interruptions to their lifecourse, including the shunting back and forth between RRT modalities, their gender, and its impact on their identity. The manifestation of the embodiment of ERF in the appearance of the external body, sexual maturity and reproductivity, was especially salient. Disclosure of health status, and exposure of the sick body, were both barriers to reaching social goals, as they were in CF (Lowton, 2004), and both were more difficult because they were discreditable, not discredited (Goffman, 1963). Like young adults with cancer (Grinyer, 2007), all aspects of transition into adulthood were affected: education, employment, and establishment of independent living arrangements; as well as peer and more intimate sexual relationships. However, the trajectory of ERF was characterised by particular uncertainty and RRT a poor substitute for the body's own organs. Thus, any progress to independent adulthood was likely to be easily reversed by future ill health. Interviewees with access to more social resources were more successful in achieving adulthood, in terms of education, employment, financial independence and living independently. Those with few personal and social resources tended to be more socially isolated and marginalised, especially if they were male.
10. CONCLUSIONS

10.1. INTRODUCTION

The focus of this thesis has been on young adults moving into adult life with a largely invisible chronic illness which is normally associated in society with mid life or old age, ERF. Firstly, it aimed to build on existing sociological and youth transition research by exploring what it meant to be chronically ill in emerging adulthood (Arnett, 2001), and how far the lived experience of ERF depended on the chronological age at which individuals were first diagnosed. Secondly it aimed to explore the interrelationships between the illness experience and social structures, and in particular to identify how different forms of social and family capital were used, from the time of diagnosis, to facilitate transition into adult life.

There is almost no sociological research on young adults with ERF and only limited work on adults (Crowley-Matoka, 2005; Gerhardt, 1990 a; Gerhardt, 1991; Kierans & Maynooth, 2001). ERF in children and young adults has a low incidence and low prevalence, and is, therefore, almost invisible in society as a disease which affects young people. It also has a different disease trajectory to diseases more frequently studied in young adults such as asthma, diabetes, cystic fibrosis, and childhood cancers (Badlan, 2006; Datta, 2003; Kazak & Nachman, 1991; Lowton & Gabe, 2003a; McDonagh, Southwood, & Ryder, 2000; Phipps & DeCuir-Whalley, 1990; Stam, Hartman, Deurloo et al., 2006; Williams, 2000a; Young, Dixon-Woods, Findlay, & Heney, 2002). ERF is characterised by uncertainty and by extreme swings in physical health, depending on whether people are living with a successful transplant or merely 'existing', as some see it, on dialysis, be that haemodialysis or peritoneal dialysis.

Very long-term dialysis is damaging to health, and eventually terminal, in that the inadequacy of the treatments in replacing normal renal function, eventually leads to premature death. A successful transplant offers a good quality of life, albeit on a complex and strict drug regime with many side effects, and its own long-term associated problems. Kidney grafts have a limited 'life', at present this ranges from a few minutes to about 20-30 years, although one or two are believed to have lasted 40 years. For adult transplant recipients, the five year graft survival rate currently ranges from 83-89%, depending on a number of factors, including whether the kidney was
from a living donor or a cadaver. For children with ERF\textsuperscript{18}, ‘comparing the 0-4 year-old cohort with the 10-14 year-old cohort of paediatric patients, 5-year survival rates for patients starting RRT in the early eighties declined from 85% to 70% with decreasing age’ (European EDTA registry data, all modalities RRT) (Brunner, Fassbinder, Broyer, Oules, Brynger, Rizzoni et al., 1988).

In the sociology of chronic illness, much recent work has focused on the subjective meanings people give to their illness experience, the interruptions to their lives, and interactions with family, friends and work. There has been less focus on the interaction between the subjective illness experience and social structures (Pierret, 2003). This study has aimed to integrate these two perspectives. Moreover, much existing work has focused on well known diseases of the middle and later years (Bury, 1982, 2002; Bury & Gabe, 2004; Charmaz, 1983, 2002; Pierret, 2003; Williams, 1984), and less work has explored relatively rare diseases in children and young adults (Atkin & Ahmad, 2001). In addition, little sociological work to date has focused on how far the age at which people are diagnosed is important for understanding the meaning of chronic illness for young adults (Grinyer, 2007), and again, what exists has focused largely on the subjective meanings of particular illnesses, often with an emphasis on psychological coping strategies (Atkin & Ahmad, 2001; Burker, Madan, Evon, Finkel, & Mill, 2009; Cameron & Leventhal, 2003; Charmaz, 1990; Moos, 2002; Schur, Gamsu, & Barley, 1999).

Within the youth transition literature, gaps with respect to chronic illness exist. Two main bodies of youth literature were relevant: literature related to the transition of so called ‘disadvantaged’ youth and young people with disabilities, and that related to ‘normal’ youth transition. In the former, there has been little focus on transition with chronic illness (Cassidy, O’Connor, & Dorrer, 2006; Evans, Rudd, Behrens, Kalusa, & Woolley, 2000; Thomson, Henderson, & Holland, 2003; Valentine, Skelton, & Butler, 2002). In the latter, the focus has been on the attainment of transition markers, and development of adult identity, often from a more psychosocial perspective (Arnett, 2000, 2001; Osgood, Ruth, Eccles et al., 2005; Salmela-Aro, Aunola, & Nurmi, 2007).

10.2. OVERVIEW OF METHODOLOGY

The rarity of ERF in children and young adults meant that finding research subjects proved challenging, and led to recruitment of participants via NHS hospital renal

\textsuperscript{18} UK and/or European ERF patient survival data for date of birth 1976-1990 incl. were not routinely collected. These are only published data found.
Interviewees (40) were selected from respondents (N=296) to a postal survey sent to all young adults with ERF aged 16-30 (N=931) being treated in fourteen geographically dispersed teaching hospitals in England, and who had expressed a willingness to be interviewed. The response rate to the survey was 32% (one follow up). Overall, fewer than 5 people did not respond positively to the request for an interview.

Most of those interviewed were in their late 20s, and they were interviewed on an ongoing basis soon after returning the survey, so that data were collected at more or less the same time. Interviewees were selected on the basis of their questionnaire responses using predetermined criteria (age of onset, complexity of renal history, modality of RRT, gender and ethnicity) as discussed in Chapter 4. The final sample was reasonably evenly distributed by age of beginning RRT, but included more older respondents (22/40 were 27 or older) and more males (24/40). Some early interviewees were under 20 years, and three appeared uncomfortable during the interview, possibly depressed. Their data were valuable but limited, and no further interviews were conducted with respondents under 20 years.

The interviewees' accounts were obtained by the researcher in face to face interviews (27) conducted mainly in their own homes, and via telephone interviews (13) where interviewees were geographically distant. The interviews were semistructured and audio recorded, with one exception, and used a topic list derived from the literature, pilot interviews, and the researcher's family experience of ERF. The first question was completely open, offering interviewees the opportunity to frame their accounts.

**10.2.1. Mixed methods**

Whilst mixed methodology has been often considered problematical in sociological research (Arksey & Knight, 1999; Barbour, 2001; Brannen, 2005; Denzin & Lincoln, 2000; Mason, 2002; Silverman, 2000; Stewart, Makwarimba, Barnfather, Letourneau, & Neufeld, 2008; Thomas, 2010), there have been calls for such work in the sociology of chronic illness (Pierret, 2003; Pound, Gompertz, & Ebrahim, 1998). The quantitative element helped gain initial support from renal physicians by offering data useful for renal service development, and allowed access to ERF patients. Moreover, from a sociological perspective, analysis of data from qualitative and quantitative

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19 ERF increases with age, so ipso facto there were more older patients in the original sample. Hospital databases varied and most only listed date of birth, gender and modality of RRT, so no refinement of selection criteria was possible.
studies of the same population of young adults with ERF, as presented in this thesis, has illustrated the strengths of mixed methodology. Where findings differed, the differences offered further insights into the lived experience of ERF in this age group; where they were similar, they offered reinforcement.

The quantitative survey data served to confirm that adult outcomes for the patients in this study were broadly similar to those reported in the psychosocial medical literature for young adults with long-term ERF treated in several European and US renal centres (Bartosh, LeVeron, Robillard et al., 2003; Broyer, Le Bihan, Charbit et al., 2004; Groothoff, 2004; Groothoff, Cransberg, Offringa et al., 2004; Groothoff, Grootenhuis, Offringa et al., 2005; Offna, Latta, Hoyer et al., 1999; Qvist, Jalanko, & Holmberg, 2003; Qvist, Narhi, Apajasalo et al., 2004). The interviewees’ qualitative data offered rich insights into the lived experience of ERF in emerging adulthood, and provided ‘explanatory’ mechanisms to help interpret the quantitative findings, most notably identifying possible explanatory factors for educational underachievement, challenges in finding employment, difficulties in leaving home, and finding new friends and/or an intimate partner. Qualitative data from parental interviews (19F, 1M) were analysed, and findings included in this thesis only where they contributed to a greater understanding of the interviewees’ own experiences. The accounts parents provided, whether as living donors and/or carers, also illustrated the emotional labour mothers in particular had undertaken, in trying to sustain the ‘normality’ of the early interviewees’ childhood experiences, as far as they were able.

For the most part the quantitative and qualitative data were complementary, the one confirmed, and in part explained, the other. However, some of the interviewees’ own survey responses appeared possibly more honest, and often bleaker, than their interview accounts. In these respects the survey data corresponded better with the mothers’ data, especially in areas where the interviewee was faced with a potentially discrediting disclosure to the interviewer. This was most marked in interviewees’ survey responses to ranked questions about the challenges of living with ERF (Q9), and open questions about their feelings, which revealed the strength of some of their negative feelings about their illness, its impact on every aspect of their daily lives, and about how little their friends and acquaintances really understood about what it meant (Q10, and 11).

Almost all interviewees, with only one or two exceptions, gave very positive, mainly factual, oral accounts of themselves. A few interviewees said they had been, or were, depressed and very few talked directly about their worries about the future or the
emotional impact of ERF on their lives, in contrast to what they, and other survey respondents, had described in the survey. Most of the prepubertal onset interviewees (0-11 years) had 'forgotten', or chosen to forget, about the traumatic events following diagnosis and initiation of RRT. In this area, the mothers' data provided particular insight into the children's and families' experiences, especially where their marriages had been put under severe strain or had broken down completely.

The author's family experience of ERF also contributed to the interpretation of the findings, in that the evidence presented accorded with her family's experience, and her experience as a carer representative on the UKT Kidney Advisory Group. Distance from this personal experience of ERF was achieved by a combination of academic rigour in the application of grounded theory in data collection and analysis, and the interviewer's learnt objectivity, gained via initial academic qualifications, training and lengthy experience in the natural sciences, together with the passage of time. Issues related to the researcher as 'insider' were discussed in Chapter 4.

10.3. KEY FINDINGS

Only about half of the older interviewees (aged 25+) had reached the widely-accepted age-appropriate milestones for young adults (Arnett, 2001; Stam, Hartman, Deurloo et al., 2006), with respect to educational attainment, employment, independence and a secure adult identity. Moreover, those who first presented with ERF when they were under 16 years were significantly less successful in education and employment than those who were 16 and over when they first became ill.

10.3.1. Subjective experiences

ERF is a socially invisible disease in young adults, and the problematic, incomplete, and over simplistic dichotomous representation of RRT: transplantation 'good', dialysis 'bad' denied the interviewees' individual lived experiences. Very few ERF interviewees presented themselves as 'ill', and those that did were socially and economically isolated and/or depressed by accumulated physical or mental health problems. All the interviewees who could, chose to 'pass for normal', rather than present themselves with the 'sickness identity' given to them by powerful older adults throughout their illness, a period of more than 25 years for some. 'Normalcy' relied on their illness remaining invisible and undisclosed, and many lived in fear of unplanned disclosure and discreditation, but they were all living with very high levels of health uncertainty, and at risk of future discrediting disruption/s of their life course. Their
adult identities appeared to be secure only in their homes, where they could abandon efforts to present as 'normal' and assume a more comfortable 'illness' identity.

Disclosure of illness status was particularly difficult in new adult social situations where it eventually became unavoidable, such as employment and intimate relationships. Interviewees employed a range of harm-minimisation strategies to protect themselves from stigma and discreditation, but nevertheless, some had experienced discrimination and rejection after disclosure in employment and intimate partnering. Difficulties in finding employment, and/or finding only insecure or part time employment, meant that a large proportion of interviewees remained living at home, dependent on their parents (N=25), and if working in temporary or sheltered employment, had low income. The few who appeared to be living 'normal' working lives recognised this was dependent on their successful transplant, and likely to be for a limited period only. Those who were unemployed found themselves living at the margins of society, neither sick nor well, neither dependent nor fully independent adults (Crowley-Matoka, 2005).

The embodiment of ERF was central to the lived experience of all the interviewees. For many it meant that 'normal' adult family life, with a job, partner and children, seemed unattainable. The physical body placed limitations on employment. Dependency on RRT, especially dialysis, created problems in the workplace, and even the 'healthiest' of the transplanted interviewees were less fit and more tired than 'normal' adults. Developing an intimate relationship meant exposing their bodies, and 'hidden from view' visible anatomical abnormalities of RRT, including for some, dialysis technologies, to the critical gaze of a partner. It also meant disclosing intimate personal information around fertility, child bearing and, for some, the inheritability of their disorder, invisible physiological effects of ERF. Those of both genders who had partners and were living independently (N=11 cohabiting, 5 less-established), had been successfully transplanted at the time they met, and most had found partners through family or cultural social networks, or the internet.

Gender made a difference. The young women had more extensive social networks than the men, who tended to be more isolated. It was notable that all six interviewees who lived alone were male, three of whom had a greater than average need for support. Unemployment particularly threatened the masculinity of the men, especially those from working class backgrounds. The gendered embodiment of ERF meant that reproductivity and parenting were experienced in different ways. At puberty, developmental delay, manifested in the late arrival of 'secondary sexual
characteristics', was experienced as acutely stigmatising by male interviewees, but could largely be hidden by the young women. In adulthood, the young women had huge concerns about pregnancy and childbirth, which threatened their health and that of any foetus, but few men had comparable concerns about their fertility, and worried more about their roles as fathers.

10.3.2. Age of onset
Qualitative data showed that it was whether the first presentation of ERF occurred before or after puberty that probably accounted for differences in adult outcomes demonstrated in the quantitative data. Qualitative analysis showed how illness disrupted the education of those who were ill in early childhood at critical moments, leading to delayed educational achievement and/or underachievement, and how most were adversely affected by family breakdown. Social relationships, both at school and in their local communities, were similarly adversely affected, with those who experienced development delay before puberty being even more affected. Some faced accumulating difficulties in establishing positive adult identities, and several prepubertal onset male interviewees became particularly socially isolated.

In contrast, those who were ill at puberty, or later, experienced biographical disruption differently from those who were ill in early childhood, with fewer 'critical moments'. Their adult identities were more developed and less permanently affected by their illness, and their education had, in most cases, proceeded without excessive interruption up to GCSE. They were also closer to their peers in terms of their physical and emotional development and maturity. No family breakdown was reported.

10.3.3. Social resources
Social and family resources were shown to be especially important in securing employment, independent living and a partner. What appeared to make a difference to the achievement of transition goals, was not only the age at which interviewees became ill, but also the amount of social, family and financial capital available to their families, and to some extent, how far they had accumulated their own.

Some interviewees were born into families with few social resources and would have been expected to have, what Evans described as limited or 'bounded' agency (Evans, 2002), a constrained ability to make individual choices about the direction of their future lives (Giddens, 1991). For these interviewees, their ill-health compounded such effects. Others had been born into families with greater financial and social
resources, including cultural resources, which mitigated some of the social impacts of their illness. These interviewees, even if in poor health and poorly educated, had more life choices, as these were facilitated by their parents' networks and family financial resources. Overall working class interviewees appeared to be more constrained in their adult lives than middle class interviewees, with male working class interviewees particularly adversely affected.

10.3.4. Summary
Interview data added depth of understanding and meaning to the survey data, helping to explain why many study participants, especially those with early onset ERF, had not reached the expected markers of adulthood in early adult life. The effects of repeated biographical disruption caused by ill health, especially at critical moments in interviewees' lives, threatened 'normalcy' and tended to accumulate. The embodiment of ERF, and underachievement, or delayed achievement, of adult independence, meant many interviewees, especially those ill before puberty, had insecure adult identities. Thus, ERF increasingly limited interviewees' agency over their own lives, constraining their choices in employment, friendships, living arrangements and partnerships. The certainty of further disruption and shortened life expectancy, limited aspirations of 'normal' adult life similar to that of their peers, and some, especially male interviewees, became socially isolated.

In contrast, chronic illness in mid and later adulthood often means loss of things already achieved: loss of previous employment, loss of social capital and financial resources, and increased pressure on their families/ intimate relationships. This study confirms the importance of chronological age in understanding the lived experience of chronic disease across the lifespan, as identified by Grinyer (2007), but provides clear evidence that a legacy of chronic illness from very early childhood creates more constraints in adult life, than constraints caused by onset of chronic illness after adolescence. This does not appear to have been explored previously.

10.4. METHODOLOGICAL CONSIDERATIONS

10.4.1. Data gathering
The interviewees were sampled from hospital patients, aged 16-30, on RRT who completed a self-completion survey instrument (response rate 32%), whose responses indicated a willingness to be interviewed, and who met the inclusion criteria. They might therefore have anticipated some of the areas to be covered. Survey respondents were likely to be healthier, physically and mentally, than others.
with ERF in the same age group. The survey was long, and designed to stand alone, so this too could have influenced response rates. Moreover, because a written survey requires a certain degree of literacy, respondents were more likely to be highly educated and academically successful than the general population. There were more older respondents to the survey, as would be expected from the increase in prevalence of ERF with increasing age; and more males, as ERF is more prevalent in males. Hospital ethnicity data were incomplete, and survey data were not collected with respect to whether respondents' first language was English.

Study participants were, of necessity, approached via NHS renal databases, and for ethical reasons, their clinician needed to be actively and demonstrably supporting the project. Any bias from the initial involvement of their physician, or the renal unit with whom they had an established relationship, was 'neutralised', to some extent, via the use of a reply-paid envelope for the return of the questionnaires directly to the researcher at her University of Surrey address. Nevertheless, respondents' relationships with their clinicians, positive or negative, might have affected their decision to participate, and/or their responses.

The age profile of the interviewee sample was affected by the decision to obtain a reasonably even distribution of age of beginning RRT, and a reasonably representative mix of modality, RRT history, ethnicity and gender. Males were over represented, but only marginally so compared with the gender distribution of those with ERF in the UK (males: females, 3:2). This resulted, in part, from difficulties in persuading female volunteers to commit themselves, when approached. There was a slight over-representation of white interviewees compared with the survey respondents (84% v 79%).

It was possible that interviewees' accounts were affected by whether or not the interviewee was alone during the interview. However, all those who were interviewed by telephone, except one, said they were alone in the room (unverifiable). This interviewee had had a stroke, and needed his mother's help in remembering key facts/experiences. For one face to face interview, a partner had entered the room, unheard and from behind the interviewer; this could have contributed to his positive presentation of self.

Interviewees' social class could only be assessed from a mixture of what they and their parents said, from visits to their own homes and those of their parents, and/or their parents' occupations, as far as these were divulged. More interviewees had
middle class family backgrounds, probably a consequence of the literacy levels the survey demanded, and the social skills and confidence needed to volunteer to be interviewed on intimate subjects by a stranger.

Thus the survey respondents and the interview sample included more individuals who were likely to be physically and mentally healthier and better educated, than the population of young adults with ERF in the UK. Those with serious clinical depression, or who were acutely ill, had more serious co-morbidities, had learning disabilities or had English as a second language, were all likely to be under-represented in the study. The findings, therefore, probably offer a more positive portrayal of the experiences of living with ERF in emerging adulthood; one which tends to minimise the real impact and suffering associated with ERF. This positive bias was compounded by the clear desire that most of the interviewees had to present themselves to the interviewer as 'normal', and living a normal life. The evidence from mothers helped to address this.

10.4.2. Interviewer and interviewee effects in conducting the interviews

The interviewer was middle aged and female, and was possibly seen as a mother figure. The interviewees knew that the researcher had family experience of ERF, which facilitated understanding and a natural flow of uninterrupted discourse, but could have compromised objectivity. This was addressed by continuing self reflection at all stages of the study. The data were 'co-created' by the respondent and the interviewer, and while, many accounts were clearly polished and rehearsed, several were 'new', in the sense that the interviewees had clearly not presented their stories to an interviewer outside the clinical setting before.

The interviewees provided what have been described in the literature as 'narrative accounts' of living with ERF, and the data suffer from the acknowledged weaknesses of data collected in this way, such as how their accounts were shaped by motive and context, and the interpretive gap that exists between the lived experience and talking about it (Bury, 2001; Hok, Wachtler, Falkenberg et al., 2007; Petersen, 2006; Riessman, 1990).

10.4.3. Strengths and weaknesses of the study

The interviews were part of a larger mixed methods study, and presented the associated challenges to ‘integrating’ the data. The detailed analysis of the interview data drew on the findings from the quantitative survey and the parents’ interview
data, for contextualisation, and it is argued, that on balance, these contributed to the interpretation of the meaning of living with ERF in emerging adulthood, and added strength to the findings. Other strengths of the study derive from the general representativeness of the survey sample of all those aged 16-30 with ERF in the UK, and from the high degree of congruence between the patient interview data and the survey data. The breadth and depth of the study were unusual which meant that individual lives were presented in a particularly wide social context.

Weaknesses in data gathering derived from the use of a hospital sample to recruit participants, and from the use of a long survey instrument, possibly a deterrent to some recipients. Arguably, some weaknesses related to 'integration' of different kinds of data, came from the dissonance between some of the patient data and the parental data, and between the interviewees', possibly more honest, open question survey responses and their interview data, but these can perhaps be explained by the sensitivity of the data in some areas. Data on intimate partnerships was difficult to obtain and the analysis relied on both interviewees' accounts and reported data from parents.

The study ignored, for the most part, more psychological approaches towards understanding the kinds of coping strategies the interviewees used, which have been well-documented elsewhere in the health-related behaviour and psychosocial medical literature (Atkin & Ahmad, 2001; Kiviruusu, Huurre, & Aro, 2007; Leventhal, Brissette, & Leventhal, 2003; Lowton & Gabe, 2003a; Moos, 2002; Olausson, Utbult, Hansson et al., 2006; Reynolds, Morton, Garralda et al., 1993; Simons, Ingerski, & Janicke, 2007; Stam, Hartman, Deurloo et al., 2006; Witenberg-Fisher, 1981).

10.5. WIDER IMPLICATIONS OF FINDINGS

The wider implications of this study are important for two very different kinds of readers. For those in renal medicine, the survey findings are important since it is the first English study to involve so many hospitals, and to be analytically independent of the NHS. Many of the main findings were statistically significant, some confirming previous findings from single centre UK and international data (Bartosh, Levenson, Robillard et al., 2003; Broyer, Le Bihan, Charbit et al., 2004; Groothoff, Cransberg, Offringa et al., 2004; Groothoff, Grootenhuis, Offringa et al., 2005; Karrfelt & Berg, 2007; Offna, Latta, Hoyer et al., 1999; Postlethwaite, Eminson, Reynolds et al., 1998; Reynolds, Morton, Garralda et al., 1993). They add new dimensions to the known body of knowledge relevant to adult outcomes of patients with paediatric presentation
of ERF. These data have sufficient strength and novelty to overcome barriers to dissemination to the relatively closed world of specialist adult nephrology.

From an NHS perspective, the qualitative data offer some new answers as to why adult outcomes vary between young adults who are in similar situations with respect to their renal health and health-related behaviour. The findings highlight the importance of considering the age of first diagnosis of ERF in designing and delivering the services they provide for young adults in adult renal units, through attaching greater importance to their continuing social development, and their position in the life course. They have presented to adult renal medicine for the first time, the delays many in the prepubertal onset group, especially, experienced in attaining the social markers of adulthood, and the kinds of social challenges they face in their everyday lives outside the medical setting, including the paucity of social resources available to some. Informal dissemination to multidisciplinary teams in adult renal medicine has been successful to date, but adult nephrologists remain hard to reach. Findings have been used to support a new initiative from the Department of Health which is providing funding for adult renal units to improve services for young adults, and young adults moving from paediatric units into adult care (DH, 2009).

More importantly, in a sociological context, the findings demonstrate how the experience of living with chronic illness varies according to both chronological age and stage in the lifecourse. Factors such as visibility/invisibility, stigma and shame, and disclosure and discreditation, are of greater importance at a point in the life course where adult identities are being formed, and adult social relationship being made; and differences from 'normal' more keenly felt when peers are apparently healthy and well. The experiences of rejection in seeking employment and forming intimate relationships may be shared by other young adults, but choices and opportunities are fewer for those who are ill, and rejection more frequent and experienced differently. Findings suggest that invisible chronic illness is particularly problematic for male masculinity at this point in the life course, in terms of unemployment and formation of peer and intimate relationships, so that chronically ill males are more likely to be socially isolated than females. For both genders, chronic illnesses which affect the 'hidden from view' appearance and sexual maturity and reproductivity, such as ERF, clearly have a huge significance in emerging adulthood.

Biographical disruption early in life related to chronic illness, but more especially before puberty, has the effect of prematurely shutting down opportunities for emerging adults to realise their potential in adult life almost before their adult lives.
have begun. This is a different kind of loss to that experienced by mid life and older adults who often lose most of what they had previously taken for granted. Older adults are more likely to anticipate and expect to deal with issues like morbidity and mortality as they get older and chronic illness becomes more ‘normal’ (Grinyer, 2007; Pound, Gompertz, & Ebrahim, 1998).

The findings contribute to a greater understanding of emerging adulthood for young people who are disadvantaged in society. Research has heretofore concentrated mainly on socioeconomic, ethnic, sexual orientation differences, and on young adults with physical and/or learning disabilities, rather than on those with chronic physical illness without concomitant disability. Interviewees’ willingness and motivation to work, and their difficulties in finding suitable work, are shared by many of those with more visible disabilities. Most interviewees were well enough to work and keen to be working, but were unable to find permanent employment and/or sustain a full-time role indefinitely. This led to a lot of unrealised potential to contribute fully to adult social life, and frustration, amongst these young adults.

10.6. CONCLUDING REMARKS

This study has contributed to two very different bodies of academic literature. On the one hand, the sociological literature on chronic illness, most of it focusing on mid life and older adult experiences of chronic illness and, on the other, more multidisciplinary youth literature on youth transitions, almost all of which has largely focused on implications of social structure for ‘normal’ and disadvantaged youth. Chronic illness experience remains outside the main body of sociological literature on disability, especially where it focuses on the ‘social’ model, but in many invisible chronic diseases such as ERF, as in many kinds of disability, the role of the physical and sexual body cannot be ignored.

Using ERF in young adulthood as an exemplar, the study has brought together sociological concepts derived from very different areas of research to reach a broader understanding of how chronic illness is experienced at a key point in the life course, emerging adulthood, and especially how this is related to the age of onset of illness. The use of mixed methods, and where appropriate integrating the qualitative interviewee data with survey data and parental data, has added strength to the findings.


Arnett, J. J. (2004). *Emerging adulthood: The winding road from the late teens through the 20s* New York: Oxford University Press


Crawford, R. (1994). The boundaries of self and the unhealthy other: reflections on health, culture and AIDS. *Social Science & Medicine, 38*(10), 1347-1365.


Gerhardt, U. (1990b). Qualitative research on chronic illness: the issue and the story. Social Science and Medicine, 30(11), 1149-1159.


Lapadat, J., & Lindsay, A. (1999). Transcription in research and practice: from standardization of technique to interpretive positionings. *Qualitative Inquiry, 5*(1), 64-68.


Marks, S.D., & Harden, P.N. (2008). Transitioning from paediatric to adult service, *Dilemmas in Renal Transplant Management* (pp. 100-107): Contract Medical Communications.


Moos, R.H. (2002). Life stressors, social resources, and coping skills in youth: applications to adolescents with chronic disorders. *Journal of Adolescent Health,* 30(Supplement), 22-29.


NCCSDO (2002). Briefing paper: the transition from child to adult health and social care: National Coordinating Centre for NHS Service Delivery and Organisation Research and Development Programme (NCCSDO).


Ussher, J., Kirsten, L., Butow, P., & Sandoval, M. (2006). What do cancer support groups provide which other supportive relationships do not? The experience of peer support groups for people with cancer. *Social Science and Medicine, 62*(10), 2565-2576.


van Campen, C., & Cardol, M. (2009). When work and satisfaction with life do not go hand in hand: Health barriers and personal resources in the participation of


Different kinds of social capital have been described in the literature in order to distinguish between the ways that social capital can be engendered and used. However, social capital remains a contested and problematic concept, with serious disagreements about what it means and how it should be measured. It is beyond the scope of this paper to provide a comprehensive review of social capital. Put briefly, early researchers such as Putman (1993) and Coleman (1988) saw social capital as a community resource, a positive entity, fostering cohesion within communities. In contrast, Bourdieu (Bourdieu, 1990; Fowler, 2000) saw social capital as an individually-held resource, that could be used to exclude as well as to include, and which interacted with other forms of capital (economic and cultural) and wider social structures to reproduce social inequalities.

In this thesis, concepts related to social capital are used as follows:

**Cultural capital**
Cultural capital is used to describe the distinctive kinds of cultural tastes, knowledge and abilities pertaining to particular social classes in society, and in particular, the ways in which the middle classes distinguish themselves as more culturally 'rich', with more cultural and linguistic competence, than the working classes.

**Social network capital**
Social network capital is used in the sense of the goodwill and interpersonal social support which comes from the network of cooperative social relationships in society, and the norms which govern these relationships (Adler & Kwon, 2002; Blaxter, 2004 (1); Putnam, 1993; Schuller, 2000; Schultz, Corman, Noonan, & Reichman, 2009). It is used as a community and family resource for social advancement, social support, advice, accessing work opportunities and so on.

**Family social capital**
Family social capital is used in the way described by Parcel at al (Parcel & Menaghan, 1993; Wright, Cullen, & Miller, 2001): that derived from family structure, composition, and the quality of family relationships.

**Human capital**
Economists use the term human capital as a measure of an individual's potential ability to contribute to the economy, largely determined by the duration of schooling and levels of educational qualifications attained (OECD, 1998 p 8).

**Health capital**
Health is regarded by economists as a kind of human capital which produces an output of healthy time, both for earning wages in the labour market and producing household commodities (Grossman, 1972). It has been argued that families invest in the health of their members to maximize total household utility (Wilson, 2002).
13. APPENDIX 2 METHODOLOGY

13.1. RESEARCH PROTOCOL (COREC SUBMISSION)

Living with transplantation and dialysis through transition to adulthood, 16-30 years

Background
In the late 1970s and early 80s, after renal transplantation had become established as the first line of treatment for end-stage renal failure adults, it began to be increasingly used as treatment of choice for end stage renal failure in children, from the age of one year upwards. The first generation of young children transplanted at this time has now reached adulthood.

The number of young children with end stage renal failure was then, and remains, numerically small. In April 2003, a total of 1330 patients under 20 years were on the paediatric database of the UK Renal Registry, with 776 of these being treated in paediatric units (475 males and 301 females) (RA 2004). At present, about 180 young adults, over 15 and under 30 years, are newly registered with end-stage renal failure per year. (Chapters 4, 5 and 13 consulted.)

However, whilst paediatric services for children are well-developed, specialist renal services for adolescents and young adults have remained underdeveloped, when compared with services for adolescents with other long-term chronic conditions such as diabetes and cystic fibrosis (Datta 2003; NCCSDO 2002, December). The NCCSDO report provides a comprehensive overview of practice relating to continuity of care for young people with chronic illness or disability, during transition from paediatric services into adult health and social care. A major reported problem is the loss of continuity of care at transition and the resultant loss of key relationships and information. For some conditions, the quality of adult service provision was less proficient than that provided by the paediatric service. Moreover it was impossible to distinguish between the young people's experience of transition between specialist services and their own physical and emotional development and transition into adulthood.

The difficulties and challenges of transition to adult care were also described in a report from a multiprofessional working party set up to review paediatric renal services (British Association for Paediatric Nephrology 2003). In this report, transition clinics were seen to offer a way of addressing some of the difficulties identified. In the same year, a report from the Royal College of Paediatrics and Child Health (RCPCH 2003) identified key concerns for adolescents in health care settings as being about access, confidentiality, consent and privacy, as well as the expertise and continuity of professionals and the type of settings in which care is provided.

Adherence to treatment in adolescents and young adults has also been seen to be an issue. Particular concern has been expressed by staff in adult renal clinics about the perceived high numbers of young people transferring from paediatric clinic who lose their graft during their teenage years or in the first few years post transfer to adult services. Some of this is anecdotal, but there is growing research evidence that adherence to treatment is a particular problem in adolescence and young adulthood (Rianthavorn, et al. 2004; Wolff, et al. 1998).
There are now a number of published studies on the long-term psychosocial impact of long-term end stage renal failure and renal replacement therapies on children who have survived into adulthood (Broyer, et al. 2004; Offna, et al. 1999; Qvist, et al. 2003; Reynolds, et al. 1993). These studies show that young adult 'survivors' exhibit more anxiety and depression, are not as successful as their peers in education and employment and have more difficulty in establishing an independent adult life, with a partner and/or having a family, themselves a possible cause of depression (Mossakowski, 2011). Parent, carer and sibling relationships are also adversely affected (Cimete 2002; Hickey 1972; Young, et al. 2003). Such studies have focused on medical and/or psychological/psychiatric variables, and have been aimed explicitly at informing improvements to service delivery and improving clinical outcomes for patients, as defined by professionals. What is striking is the absence of knowledge about patients' everyday experiences of living with renal failure at all ages and how they look after themselves.

This study, in contrast, will provide information about the experiences of living with renal failure as a young person entering adult social life. It will allow young adults to articulate in their own words some of the challenges which face them as they manage transition from home and school to independent housing, further education, employment and/or training, and adult intimate relationships (Thomson, et al. 2002). This is important because it will bring patients' own accounts of their illness, of how they manage their complex lives, and of how they look after themselves, to professional debates about the psychosocial impact of renal failure, adherence to treatment and graft loss in younger transplant patients.

There is now wide acknowledgement both within medicine and outside, that sociological approaches to understanding health and illness have brought additional benefits to patient care, focused as they are on the meaning of illness to patients, on social life and wider society.

Sociological ideas about adulthood examine (adult) human life and development in terms of the life course, a social process in which people's passage through various stages in their lives is linked to their social roles and culture. This is in contrast to a more scientific approach where people are seen as passing through a lifecycle structured by defined linear biological stages (birth, reproductive phase, post-reproductive phase and death) which are separated by biological events such as puberty and menopause. The life course, on the other hand, is structured by key events in people's social lives such as starting school, entering employment, getting married, having children, parenthood, bereavement and retirement.

In early discourse of this kind the body itself appears to have lost all salience, whilst from a common sense perspective, the body is clearly important. In chronic illness particularly, the physical reality of the disease cannot be ignored.

More recent sociological debate about how people experience their bodies and how they articulate this experience, has lead to the concept of an embodied life course which encompasses and enmeshes both culture and biology (Kelly and Field 1996; Nettleton and Watson 1998; Watson 2000). Watson (2000 p7) argues that 'embodiment is the personal ground of culture, structure and behaviour and that focusing on embodied experience enables us to look at health in the context of these themes'. Thus it is the embodied human who experiences a life course socially structured by key life events.

This study will build on existing knowledge and understanding of the human life course, embodiment of health and the meaning of chronic illness from a sociological perspective, drawing on key texts and papers in medical sociology including classical
work about the stigma of having a chronic disease and what this means for how we present ourselves in the social world (Goffman 1963), and ideas about chronic disease as a disruptive event in people's lives (Bury 1982). Lay perspectives of health and illness; for example, patients' views of how and why they became ill and their accounts of the impact of illness on their lives will also be analysed. Here I will draw on key work by Gareth Williams (Williams 1984) who describes how people with chronic ill health undertake a process of 'narrative reconstruction' to account for what has happened to them and why; how they try to repair breakdown between their bodies, themselves and their social world by linking up various parts of their story or biography and realigning their past selves with their present selves. Simon Williams has looked at the genesis of disease in a different way, suggesting that biographical disruption and other significant life events can have a role in the creation of chronic disease (Williams 2000) as well as being an outcome of chronic disease. This may contribute to our understanding of the impact of chronic physical illness on mental health.

Chronic illness experience in young adults and renal disease are two relatively under-researched areas in medical sociology. Little work exists on chronically ill young adults and much of this has focused on more common disease groups (Lowton and Gabe 2003; While and Mullen 2003; Williams 1998). The small amount of existing sociological literature on renal failure has focused on older patients (Gerhardt 1990; Gerhardt 1991; Lehoux, et al. 2004). Thus this project will, for the first time, explore and describe the lived experience of young adults with chronic renal failure, its psychosocial impact on their lives, and, through established sociological research methodology, bring new insights into explanations about young adults' health and illness related behaviours, including adherence to treatment regimes.

**Objectives**

*Principal objective*

To create a new body of knowledge, understanding and theory which is valid and reproducible, about how young adults on dialysis and with a transplant manage their lives and health, and which can be used to inform and develop NHS services.

*Secondary objectives*

i) To gain a deeper understanding of the challenges facing young adults, from their own perspective, as they enter and establish themselves in independent adult life with long standing end stage renal failure (ERF).

ii) To explore family and/or carers' perspectives of the challenges facing young adult patients as they enter and establish themselves in independent adult life with long standing end stage renal failure (ERF).

iii) To explore how far key NHS staff, identified by the young adults, are aware of the special needs of younger adult patients who present with long-term illnesses and with extensive experience of nephrology and transplant services.

iv) To raise the awareness of health and social care professional staff about the needs of young adult patients at transition from paediatric care to adult care as established in this study, so that, in the care they provide, they take account of the issues the young adults are facing in managing their health, at the same time as they are managing the challenges of entering independent adult life.
v) To inform the development of health and social service design and delivery for this group so that service provision can better meet their needs, and in so doing encourage and support adherence to difficult treatment regimes.

Research design and methods

This will be primarily a qualitative research project using questionnaires and interviews with hospital patients and staff, situated in sociological discourse, but drawing on analytical approaches from sociology, psychology and behavioural medicine.

Hospitals (15) have been selected which serve large population areas in England for ease of access at the interview stage (see below). Some adult hospitals have associated paediatric units, some do not. The hospitals are:

<table>
<thead>
<tr>
<th>Hospital Trusts</th>
<th>Renal Transplant Centre</th>
<th>Age range treated</th>
<th>Prevalent all adult total RRT 31.12.3 (Renal Registry 2004)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Birmingham, University Hospital Birmingham Foundation Trust</strong></td>
<td>Yes, Queen Elizabeth Hospital</td>
<td>Adult and paediatric</td>
<td>NA</td>
</tr>
<tr>
<td>Bristol, North Bristol NHS Trust</td>
<td>Yes</td>
<td>Adult and paediatric</td>
<td>1060</td>
</tr>
<tr>
<td>Cambridge University Hospitals NHS Foundation Trust</td>
<td>Yes, Addenbrooke's</td>
<td>Adult, no paediatric</td>
<td>746</td>
</tr>
<tr>
<td>Coventry, University Hospitals Coventry and Warwickshire NHS Trust</td>
<td>Yes, Walsgrave</td>
<td>Adult, no paediatric</td>
<td>581</td>
</tr>
<tr>
<td>London, Great Ormond Street*</td>
<td>Yes</td>
<td>Paediatric, no adult</td>
<td>155 (all ages April 2003, 67 over 15 years)</td>
</tr>
<tr>
<td>London, Guy’s and St Thomas’ NHS Foundation Trust</td>
<td>Yes</td>
<td>Adult and paediatric</td>
<td>1200</td>
</tr>
<tr>
<td>London, Hammersmith Hospitals</td>
<td>Yes</td>
<td>Adult, no paediatric</td>
<td>1088</td>
</tr>
<tr>
<td>London, Kings College Hospital Trust</td>
<td>No</td>
<td>Adult, no paediatric</td>
<td>574</td>
</tr>
<tr>
<td><strong>London, Royal Free Hampstead NHS Trust</strong></td>
<td>Yes</td>
<td>Adult, no paediatric</td>
<td>NA</td>
</tr>
<tr>
<td><strong>London, Barts and The London NHS Trust</strong></td>
<td>Yes</td>
<td>Adult, no paediatric</td>
<td>NA</td>
</tr>
<tr>
<td>London, St George’s Healthcare NHS Trust (St Helier figures)</td>
<td>Yes</td>
<td>Adult, no paediatric</td>
<td>891</td>
</tr>
<tr>
<td><strong>London, St Mary’s NHS Trust</strong></td>
<td>Yes</td>
<td>Adult, no paediatric</td>
<td>NA</td>
</tr>
<tr>
<td>Nottingham City Hospital NHS Trust</td>
<td>Yes</td>
<td>Adult and paediatric</td>
<td>814</td>
</tr>
<tr>
<td>Oxford Radcliffe Hospitals NHS Trust</td>
<td>Yes, Churchill</td>
<td>Adult, no paediatric</td>
<td>1398</td>
</tr>
<tr>
<td>Portsmouth Hospitals NHS Trust</td>
<td>Yes, Queen Alexandra</td>
<td>Adult, no paediatric</td>
<td>1059</td>
</tr>
</tbody>
</table>

*(GOS, 2003)
** data not available from Renal Registry 2004
Renal Association Registry data from all renal units across the UK suggest that the total number of young adults (aged 16-30) falling within the scope of the research is approximately 1500 (RA 2004). A national survey is beyond the scope of this study. It is anticipated that the questionnaire will be sent out to all eligible patients in the participating hospitals (about 500 patients). The survey will also provide the basis for selecting 40 volunteers for interview.

The research comprises three distinct methodologies:

1. **Patients' self-completion questionnaires**

Self-completion questionnaires will be sent to all young adults undergoing RRT in the age range 16 to 30 years on 31 December 2005 in the 15 participating hospitals.

These will collect both quantitative data and some qualitative data relating to:

- demographic variables, such as age, gender, race, family resources, education/employment status etc,
- disease specific variables, such as aetiology of disease, age and date of first diagnosis; including cases where young adults have lost a functioning graft within 2 or 3 years of adult unit attendance;
- social variables, such as social networks, social life; hobbies etc;
- health and health service variables, such as health-related behaviours, emotional health, clinic experience, and the challenges of living with end stage renal failure.

The questions have been informed by sociological theory and by the findings of preliminary informal interviews with young adult renal patients (5) already carried out. The same volunteers have been involved in developing and piloting the questionnaire.

The questionnaires will be analysed to provide a picture of the social life, health behaviours and clinic experience of the population studied and will yield quantitative data which will enable the findings to be compared with those reported in the literature (Broyer, et al. 2004; Douglas, et al. 1998; Englund, et al. 2003; Groothoff, et al. 2004; Offna, et al. 1999; Qvist, et al. 2003; Reynolds, et al. 1993; Vasquez, et al. 2003). Demographic data will enable selection of interviewees, so that as far as possible there are equal numbers of male and female patients, those on dialysis and those with a functioning kidney transplant, paying some attention to social and cultural diversity (see below).

Response rates of 30-40% are expected, yielding 150 - 200 questionnaires for analysis. A reminder will be sent out after one month if no reply.

The questionnaires will be used to identify young adults willing to be interviewed.

2. **Patient face-to-face in depth interviews**

Face to face interviews (each 60-90 minutes) with young adults (40) will form the main part of the study. Young adults who have been on renal replacement therapy for a minimum of five years, beginning when they were under 18 years, will be selected from those volunteering to participate. The interviews will explore in depth the issues raised in the questionnaires, and sociological concepts such as biographical disruption, stigma, identity, normalcy, disclosure of illness, and presentation of self. Patients will be interviewed, as far as possible, alone.
Equal numbers of male and female participants will be recruited for interview. As forty interviews are planned, this modest number means that further formal subdivision of the group is not seen to be useful. However, as far as possible equal numbers of those on dialysis and transplantation will be interviewed and efforts will be made to include young adults at different stages of the transition to adult life and from diverse social, educational, cultural and religious backgrounds.

These face to face interviews with patients will last between 60 and 90 minutes, and are expected to take place in the participants' own homes or at a mutually agreed suitable venue. For this reason, providing the other criteria described above are met, interviewees who can be reached easily from London will be sought. Permission will be sought for the interviews to be tape-recorded.

The interviews will also be used to identify named key professional medical, nursing and support staff (see below).

3. Semi-structured interviews with staff and carers

i) Semi structured face to face or telephone interviews (up to 40 in total) will be carried out with a small number of key health and social care professional staff including specialist nurses (2), transplant surgeons (1), renal physicians (2) dieticians (1), counselling/psychology services (1), social workers (1) in five selected adult units nominated by young adult interviewees. These will include both hospitals where a specialist transition service already exists, and those where there is no specialist provision. The focus of the interviews will be to explore in greater depth the perceived strengths and weaknesses of existing health service provision at transition to adult services and views on how services might be improved. Questions will be asked about staff perceptions of the challenges facing young people as they enter independent adult life with a chronic life threatening disease.

ii) Semi structured interviews will also be conducted with parents, carers and/or partners (up to 40 in total) to explore in depth their understanding of the psychosocial impact of end stage renal failure on the renal patient/s in their family at transition into adulthood.

Recruitment

1. Patient participants meeting the inclusion criteria for the questionnaire survey will be identified by NHS staff from case records in the participating Trust renal units. NHS staff will then send out, on an agreed date, complete sets of paperwork (the covering letter, a letter from the local clinician collaborator, the patient information sheet, the consent form, the self-completion questionnaire, and a reply paid envelope addressed to the researcher at the Department of Sociology, University of Surrey), as provided to them in stamped envelopes in sufficient numbers by the researcher. There are expected to be about 30-40 per hospital. Non-responders will be followed up once after one month.

2. Patient interviewees will be recruited via the self-completion questionnaire and their expressed willingness to be interviewed on the proforma. The patient information sheet and consent form will be used again immediately prior to the interview.

3. NHS staff interviewees will be identified by the participants, approached by email or telephone and recruited by the researcher.
4. Parent/carer interviewees will be identified by the young adult participants and interviewed separately only with the participant's written permission.

Advertising is not anticipated, however if insufficient participants are identified then:

i) participants will be recruited by recommendation of existing participants (snowballing);
ii) by advertising on clinic notice boards;
iii) via the services offered by the National Kidney Federation;
iv) the British Kidney Patients' Association has offered to advertise the research in their newsletter.

**Inclusion criteria for young adults**

Survey: all young adults between 16 years and 30 years and registered with the 15 participating units will be included in the initial questionnaire survey. About 500 patients are expected to meet these criteria.

Interviews: young adults between 16 years and 30 years with a minimum of 5 years' experience of renal replacement therapy (RRT) beginning when they were under 18 years.

These age criteria are based on statistical evidence from UKTransplant (email communication) that the risk of graft failure is greatest in the 11-17 age group. Other research literature (Rianthavorn, et al. 2004; Wolff, et al. 1998) supports the hypothesis that adolescence is a critical time for graft loss.

**Exclusion criteria for young adults**

Patients who are not sufficiently well to participate. Advice will be taken from clinical staff about whether any participant is well enough to participate at the time of recruitment.

**Data analysis**

**Questionnaire data:**

Questionnaire data will be analysed and presented as part of the context in which the qualitative data will be considered.

Sophisticated statistical analysis is not appropriate for this study. Instead, simple statistics and descriptive summary data of demographic variables will be produced in tabular form, appropriate to the number of responses to the questionnaire (N=150-200 expected).

Textual responses to open survey questions will be searched for key issues and themes and these will inform any further development of the in depth interview schedule.

**Interview data:**

*Interviews with young adults*
Interview transcripts with young adults will be transcribed verbatim and the data generated will be analysed by a social constructionist version of grounded theory (Charmaz 1990). Social constructionist here refers to participants' own construction/creation of definitions, ideas, understanding and knowledge about their illness and the researcher's own constructions developed by studying those of the participants. Grounded theory has 'established procedures that produce substantive theory or conceptual definitions of reality that are valid, verifiable and applicable ' (Watson 2000). It is particularly useful in making sense of informants' own accounts that contain 'subjective phenomena that are best interpreted from the perspective of the informant' (Watson 2000 p8). The theory begins by asking general research questions rather than beginning with a hypothesis to be tested. The initial research questions are informed by the literature search, by pilot interviews and by the interviews, in an inductive-deductive process, as they progress. Early interviews influence the conduct of later interviews, as on-going analysis of the collected data suggests emergent concepts and categories to be explored further. At the end of the process, categories are created which explain and conceptualise the data itself, common-sense understanding of the data and theoretical interpretations of the data; the latter based on key medical sociological concepts.

The strength of grounded theory lies in its closeness to the data itself and the rigour of the analytical methodology in developing relevant categories for which there is repeated evidence in the data. A set of explicit analytic guidelines and procedures exist for grounded theory and will be followed.

**Interviews with parents/carers/partners**

Interviews with family and carers will be transcribed and descriptive data used to explore the status and validity of the accounts given by the young adult participants, as well as to provide a different perspective on the challenges of young adults' transition into adulthood.

**Interviews with staff**

Interviews with staff will be transcribed and descriptive data presented within relevant categories as determined from the interview transcripts. These are expected to provide information and contextual material and will not be subjected to rigorous grounded theory analysis.

**Monitoring**

The work will be monitored by my academic supervisor at the University of Surrey, Department of Sociology, Professor Sara Arber.

**Reporting**

The findings will be written up as a PhD thesis at the University of Surrey and published in academic and professional journals.

Opportunities will be sought to present the findings at professional conferences and seminars in both medical sociology and renal medicine.

Reports to local ethics committees will be presented as required.
Recommendations will be made to the participating renal units about how NHS service delivery and support mechanisms for young adult patients can be better tailored to the needs of young adults.

References

British Association for Paediatric Nephrology 2003 'Review of multi-professional paediatric nephrology services in the UK - towards standards of equity and care'.


GOS 2003 'Great Ormond Street Hospital NHS Trust Renal Unit Third Annual Report: April 2002 to April 2003'.


NCCSDO 2002, December 'Briefing paper: the transition from child to adult health and social care': National Coordinating Centre for NHS Service Delivery and Organisation Research and Development Programme (NCCSDO).


Research into living with transplantation and dialysis as a young adult

I am carrying out research into what it is like to grow up with kidney failure. This involves interviewing a small number of young adult patients, carers and staff in renal units within England. I will also be sending out a questionnaire to about 200 patients.

I am writing to ask you if you would be willing to take part in this research.

The main purpose of the research is to improve health outcomes for young adults with kidney failure and who are on dialysis or living with a transplant by gaining a better understanding of the challenges you face as you enter and establish yourself in independent adult life.

As well as talking to you, I will also be talking to staff at your renal unit to see how far they are aware of the special needs of younger adult patients who have their illness for a long time and have had a lot of previous experience of renal care. I would also like to talk to your parents, carer or partner, but only with your written permission.

The questions I will ask have been tried out with a small number of patients already. They said that they were very happy to talk about their experiences and afterwards said that it had been helpful for them too.

Taking part in both the questionnaire and the interviews is voluntary, but I hope that you will be willing to take part.

I attach an information sheet, a consent form, a copy of the questionnaire and a reply-paid envelope.

If you would prefer to answer the questions electronically, I will send you them as an email attachment if you email me at: m.h.lewis@ntlworld.com. I can also be contacted the above address or by telephone on 01372 725716.

Thank you very much for considering taking part.
Dear (insert patient name)

Living with transplantation and dialysis, transition to adulthood

I am writing to invite you to take part in a research study being carried out at the University of Surrey which is looking at how kidney failure affects the lives of young adults. It involves completing a short questionnaire (about 20 minutes) and, if you are happy to do more, volunteering to be interviewed by the researcher for about an hour at home.

Please find enclosed a research participants' pack which contains:
- a letter from the researcher at Surrey University
- a patient information sheet
- a consent form
- a questionnaire
- a reply paid envelope in which to return the questionnaire and consent form to Surrey University

This is an area of work which is not well-researched and which will in time benefit all young adults living with kidney failure. I am pleased to give it my support and I hope that you will also think it is worth supporting and will find time to complete the questionnaire and return it to Surrey University.

If you are happy to take part, please return the completed questionnaire and signed consent form by (insert date 1 month after date of letter)

With best wishes

Yours sincerely

Local collaborator
(insert) NHS Trust
13.4. PATIENT RECRUITMENT ADVERTISEMENT

Kidney patient volunteers needed

We would like some help in improving health services for people like you:

- Have you been on dialysis or had a transplant for more than 5 years?
- Are you over 16 and under 30 years?
- Would you be happy to talk to a researcher from Surrey University about what it's been like living with renal failure?

We would like to hear your views about living with kidney failure and about your NHS treatment to help improve health services for young adults with renal failure (on dialysis or with a transplant), especially at transfer from paediatric to adult care and afterwards in adult units.

If you are interested in participating or would like more information, please get in touch with:

Helen Lewis
Department of Sociology
University of Surrey
Guildford
Surrey, GU2 7XH
Tel: 01372 725716
email: h.lewis@surrey.ac.uk
13.5. SURVEY INSTRUMENT

Living with transplantation and dialysis as a young adult

This short questionnaire is to ask you what life is like for you as a young adult living with a renal transplant or on dialysis. It is part of a research project being carried out at Surrey University, which aims to help you and people like you to stay well longer and obtain better health care.

Your replies will be confidential and you (and the hospital where you are looked after) will not be named on my records nor on anything I will write when the research is finished.

Attached is an information sheet and consent form. Please read the sheet and sign the consent form before you do the questionnaire.

I hope you will complete the questionnaire as young adults I have already talked to are very keen for this research to be as comprehensive as possible. It should take 15 to 20 minutes to complete.

At the beginning are some questions about you, which will help me to understand a bit more about your answers later. Please ask me for a large print version if it would be helpful (Helen Lewis: m.h.lewis@ntlworld.com; tel: 01372 725716).

Please tick or write in the boxes (for more room, please write on an extra sheet of paper).

1. About you

   a. When were you born? ____/____/____        b. Are you: Male □? Female □?

   c. Where do you live now? (town/nearest town only)

   d. Who do you live with?
       your family in your parent/s home □  your partner □  friends □  alone □

   e. Is the home you live in: rented? □  bought (being bought on mortgage)? □

   f. How many children have you, if any?

   g. How many brothers and sisters have you, if any?
      Number of brothers  Age of brothers
      Number of sisters  Age of sisters

   h. What is your height in metres? ____ What is your weight in kilograms? ____

2. To what ethnic group do you belong? Are you

   White □  Black □  Asian □  Other □
   If other, are you Mixed race □  Arab □  Greek Cypriot □  Turkish Cypriot □  None of these □  (tick one box).
3a. What educational level have you reached so far?
   GCSE □  A level or equivalent □  First degree or equivalent □  Higher degree □
   Other □  Please specify: ________________________________
   None □

3b. What is your highest science/biology qualification, if any?

4a. Are you employed at the moment?
   Yes □  If yes, is it part-time paid work □  full-time paid work □  voluntary work □
   other □
   No □  If no, are you a student □  not well enough to work □  can't find suitable work □

b. What kind of work do you do?


c. What is your monthly-earned income?
   None □  less than £500 □  £501-£1000 □  £1001-£1500 □  £1501-£2000 □ over
   £2001 □

4d. What is your monthly-unearned income?
   None □  less than £200 □  £201-£500 □  £501-£1000 □ over £1000 □

e. Where does your unearned income come from?


5. Questions about your kidney failure

a. When did your kidneys fail (when did you first have dialysis or a transplant)?
   Month___  Year ___

b. How old were you then? __________ years

c. What caused your kidneys to fail?


d. What kidney replacement treatment are you on now? (please tick)
   Working transplant □  Haemodialysis □  CAPD/CPD □  APD □

e. How long have you been on this treatment?
   Up to one year □  1-2 years □  2-3 years □  3-4 years □  4-5 years □
   5-10 years □  more than 10 years □
f. Please tell me about your treatment history (including your treatment now)

<table>
<thead>
<tr>
<th></th>
<th>How many times?</th>
<th>Which year/s did you start?</th>
<th>For how long?</th>
<th>Why the change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any transplants</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Haemodialysis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CPD/CAPD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>APD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

g. Do you see yourself as having a disability? Yes ☐ No ☐ Sometimes ☐
Are you registered as a person with a disability? Yes ☐ No ☐

h. Where do you get personal help and support? (tick as many as apply)
Family ☐ friends ☐ partner ☐ Kidney Patients' Association ☐ internet ☐ renal unit medical staff ☐ renal unit psychologist ☐ renal unit counsellor ☐ renal unit social worker ☐ teacher ☐ family therapist ☐ no-one ☐ other, please specify ☐

6. Questions about how you look after yourself

a. How important to you is:

<table>
<thead>
<tr>
<th></th>
<th>Very important</th>
<th>Quite important</th>
<th>Not very important</th>
<th>Not at all important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Looking good?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Feeling good about your appearance?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Eating healthily?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Being as fit as you can be?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Taking your medication?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Attending clinic regularly?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Checking your own blood results?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Being an expert or knowledgeable patient?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Feeling some personal control of your health?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Complying with advice about your treatment or health?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

b. What do you think is the best way for you to keep well?
7. Questions about your everyday life

a. How important to you is:

<table>
<thead>
<tr>
<th>Having one or two close friends or family?</th>
<th>Very important</th>
<th>Quite important</th>
<th>Not very important</th>
<th>Not at all important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Having a large number of friends?</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Having an intimate partner/husband/wife?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being able to join in with all that your friends do?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meeting new people and doing new things?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doing the same things socially every week or month?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being well enough to work?</td>
<td></td>
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<tr>
<td>Having a paid job?</td>
<td></td>
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<tr>
<td>Having a voluntary job?</td>
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<tr>
<td>Studying or training?</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Having enough money to be financially independent?</td>
<td></td>
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<tr>
<td>Having a religious faith?</td>
<td></td>
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<tr>
<td>Having a hobby or interest?</td>
<td></td>
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<tr>
<td>Having access to a computer and the internet?</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Telling people you work with/study with about your illness?</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

b. How often do you:

<table>
<thead>
<tr>
<th>Have a drink of beer, wine, spirits or similar?</th>
<th>Every day</th>
<th>Most days</th>
<th>Weekly</th>
<th>Rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have a cigarette/s?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eat 5 pieces of fruit and vegetables?</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Take exercise or take part in a sport?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Go out socially with family?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Go out socially with friends?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Miss taking your medication?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Miss outings because you feel unwell?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

c. What sort of things do you like doing best?

8. Questions about your current hospital clinic experience

a. Which hospital looks after you on a regular basis? _______________

b. Are you attending an adult renal clinic now?  □  a paediatric renal clinic now?  □
c. If you are attending an adult clinic, have you ever attended a paediatric clinic? Yes □ No □

e. Clinic experiences

Is your appointment at a time convenient for you? □ □ □ □ □
Is your clinic appointment on time? □ □ □ □ □
Does it interfere with your working/studying? □ □ □ □ □
Are there other young adult patients at your clinic? □ □ □ □ □
Can you see the doctor you want to see? □ □ □ □ □
Can you see a social worker if you want? □ □ □ □ □
Can you see a dietician if you want? □ □ □ □ □
Can you see a counsellor if you want? (see also below) □ □ □ □ □
Do you understand what your doctor tells you? □ □ □ □ □
Do you feel you can trust the doctor who looks after you? □ □ □ □ □
Do you understand what your nurse tells you? □ □ □ □ □
Do you feel you can trust the nurse who looks after you? □ □ □ □ □
Do you feel that clinic staff understand what you tell them? □ □ □ □ □
Would you like to see a counsellor or psychologist if one were available? □ □ □ □ □

f. What are best things about being at your clinic?

____________________________

____________________________

g. What are worst things about being at your clinic?

____________________________

____________________________

9. Questions about the challenges of having end stage renal failure

a. How far has having renal failure:

<table>
<thead>
<tr>
<th>Completely</th>
<th>A lot</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>Upset your plans for the future?</td>
<td>□ □ □</td>
<td>□ □ □</td>
<td>□ □ □</td>
</tr>
<tr>
<td>Prevented you from getting the qualifications you want/ed?</td>
<td>□ □ □</td>
<td>□ □ □</td>
<td>□ □ □</td>
</tr>
<tr>
<td>Prevented you from doing the job you want/ed?</td>
<td>□ □ □</td>
<td>□ □ □</td>
<td>□ □ □</td>
</tr>
<tr>
<td>Made it hard to get any job?</td>
<td>□ □ □</td>
<td>□ □ □</td>
<td>□ □ □</td>
</tr>
<tr>
<td>Made it more difficult to make close friends?</td>
<td>□ □ □</td>
<td>□ □ □</td>
<td>□ □ □</td>
</tr>
<tr>
<td>Made it more difficult to keep friends?</td>
<td>□ □ □</td>
<td>□ □ □</td>
<td>□ □ □</td>
</tr>
<tr>
<td>Made you feel very short of time for other things?</td>
<td>□ □ □</td>
<td>□ □ □</td>
<td>□ □ □</td>
</tr>
<tr>
<td>Made it difficult to talk about yourself?</td>
<td>□ □ □</td>
<td>□ □ □</td>
<td>□ □ □</td>
</tr>
<tr>
<td>Made you feel abnormal or different from other people?</td>
<td>□ □ □</td>
<td>□ □ □</td>
<td>□ □ □</td>
</tr>
<tr>
<td>Made you upset about the scars on your body? (added after pilot)</td>
<td>□ □ □</td>
<td>□ □ □</td>
<td>□ □ □</td>
</tr>
<tr>
<td>Made you worry about the future? (added after pilot)</td>
<td>□ □ □</td>
<td>□ □ □</td>
<td>□ □ □</td>
</tr>
<tr>
<td>Made you more dependent on friends and family than you like?</td>
<td>□ □ □</td>
<td>□ □ □</td>
<td>□ □ □</td>
</tr>
<tr>
<td>Made you more dependent on strangers than you like?</td>
<td>□ □ □</td>
<td>□ □ □</td>
<td>□ □ □</td>
</tr>
</tbody>
</table>
b. Have there been any good things about having renal failure?
Yes □ No □ If yes, please tell me about them.

10. Questions about how you've been feeling over the last month or so

a. Feeling over the last month

<table>
<thead>
<tr>
<th></th>
<th>All the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you been feeling well?</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Have you been having pain?</td>
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<tr>
<td>Have you been feeling full of energy?</td>
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<tr>
<td>Have you been feeling tired or worn out?</td>
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<td></td>
<td></td>
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<tr>
<td>Have you been feeling happy and peaceful?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you been feeling worried or anxious?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you been feeling downhearted or depressed?</td>
<td></td>
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<tr>
<td>Have you been feeling lonely or isolated?</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you felt like seeing your friends?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you been feeling pressure to be cheerful?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you been talking to friends about how you feel?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you been talking to family about how you feel?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

b. Is there anything else you want to say about how you've been feeling?

11. Questions about the wider world

a. What do you think and feel about the way people with kidney disease are written about in newspapers and seen in TV programmes?
b. Tell me about how much your friends really understand about living with kidney failure or with a transplant?


c. What do you think casual acquaintances think if they know that you’re living with dialysis or with a transplant?


d. What do you think would be the best thing the NHS could do to improve the quality of your life at the moment?


12. Anything else you want to say?


Are you willing to be interviewed for about an hour in your own home or another private venue about your experiences of living with kidney disease, but talking in a bit more detail?

Yes ☐ No ☐

If yes

Please provide your name contact details below:
Name:
Home address:

Tel: Landline
Mobile

Email:

Thank you very much for completing the questionnaire.
Please return it to me in the stamped addressed envelope provided. If you prefer to complete it electronically, please email me at h.lewis@surrey.ac.uk

Helen Lewis, Department of Sociology, University of Surrey, Guildford, Surrey, GU2 7XE
13.6. PATIENT INFORMATION SHEET

Surrey University headed paper

Information sheet for participants v3 8.2.6
Living with transplantation and dialysis as a young adult

You are being invited to take part in a university-based research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of the study?

To improve health outcomes and NHS services for young adults on dialysis or living with a kidney transplant.

The study is expected to last three years. Questionnaires will be sent to approximately 200 patients in different renal units and 40 patients will be interviewed. Up to 40 parents and guardians will also be interviewed with written permission from the young adults in each case. A small number of NHS staff will be interviewed too.

Why have I been chosen?

You have been chosen because you had renal failure as a child or young adult and have gained a lot of experience that can help NHS staff and others to improve services. All patients with renal failure aged between 16 and 30 have been chosen at your hospital, and those at 14 other hospitals too.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign the consent form below. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive from your hospital. The hospital staff will not know who has been interviewed.

What will happen to me if I take part?

You will receive a short questionnaire to complete, by post (or by email attachment if you ask for this). The questionnaire will also ask you whether you are willing to be interviewed and ask you give me your contact details.

I will be interviewing you myself over the next year. Each interview will last 60-90 minutes. Interviews will take place at your own home if you wish, or at an agreed private venue. With your permission, the interviews will be taped. I will transcribe the interviews myself and keep them, without your name and address, on my computer at my own home, protected by a secret code. Travelling expenses are available if you wish to travel to a convenient venue.
What are the possible disadvantages and risks of taking part?

You will be asked to talk freely about your own experiences of living with kidney failure and how it has affected your life, as you have got older. There are no particular disadvantages or risks to you if you do this and you will not be asked to talk about things that you do not want to talk about. But, if you find any aspect of this upsetting, then the interview will stop. I will also provide information about local confidential support services.

What are the possible benefits of taking part?

We hope that your experience will help other people with renal failure, and will help your own renal unit and the NHS to provide improved services for young adults. Other young adults who have already been interviewed found it a useful thing for themselves, as they were able to talk to someone independent of their hospital who did not know them and was not concerned with their treatment.

What if something goes wrong?

Nothing is expected to go wrong, however, if the interview is held at a venue other than your own home, then Surrey University has insurance which covers any injury at the time of interview.

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. If you find you have a concern about any aspect of this study, please speak to me on 01372 725716 and I will do my best to answer your questions. If you remain unhappy and wish to complain formally, you can speak to Professor Sara Arber on 01483 686973 at the University of Surrey or use the NHS Complaints Procedure. Details about how to do this can be obtained from your hospital PALS office.

Will my taking part in this study be kept confidential?

Any information about you which leaves the hospital, and all data I collect about you during the course of the research, will have your name and address removed, and will be kept strictly confidential so that you cannot be recognised from it. All my processes for handling, storing and destroying your data will be compliant with the Data Protection Act 1998.

It will be stored securely as coded anonymous data on my home computer, protected by a password. Parts of the anonymised data will be also stored on the secure area of the University computer. This is also password protected. It will be used to write my reports on the study and destroyed as soon as it is no longer needed. Parts of the anonymised data will be discussed with my academic supervisor only.

It is possible that your GP will be notified, with your permission, that you are taking part in the research. Your renal unit will decide if this is necessary.

What will happen to the results of the research study?

The results will be written up in the form of a research report and you will be provided with a summary of the findings. This should be available during autumn 2007.
The findings will also be given to the renal units that have participated and will be presented at conference and meetings that kidney doctors and nurses attend. If I use information about you or anything you say when I report on this research it will be anonymised so that you cannot be recognised.

**Who is organising and funding the research?**

I am organising and funding the research which is being sponsored by the University of Surrey.

**Who has reviewed the study?**

This study was given a favourable ethical review by Wandsworth Local Research Ethics Committee.

**Formal consent**

Please sign all three copies of the attached formal consent form if you are willing to participate. I will then give you a copy of this sheet and a copy of the consent form.

**Contact for Further Information**

Contact: Helen Lewis, Department of Sociology, University of Surrey, Guildford GU2 7 XE  
Email: m.h.lewis@ntlworld.com  
Telephone: 01372 725716

Thank you very much for considering taking part in this study.
13.7. INTERVIEWEE TOPIC GUIDE

Tell me what it is like living with kidney failure as a young adult

How has it affected your life plans?

What's it like at work/at school/college?

How do you manage the practicalities at work/school/college (especially for dialysis patients)?

Probe: phone calls, technology, sterility, supplies at work, disposal of supplies, embarrassment, drink (if on dialysis)

What's it like at home?

Probe: relationships with parents/carers, siblings

How has being ill affected your social and family life.

Probe: Your friends: numbers, closeness; your leisure interests; boyfriends/girlfriends/potential partners; having children; your education; financial situation

How much do you talk to people about your illness

Probe: to casual acquaintances; friends at work/college/work; new boyfriend/girlfriend/potential partners; strangers

How much do you think other people/your friends/the wider community know about kidney disease?

Probe: media, publicity

What do you now think about your own health, fitness?

How do you feel about your body? Your appearance, height, weight, scars

What do you do to stay as well as possible?

Probe: medication, exercise, eat well, alcohol, smoking,

What keeps you sane?

Probe: religion, meditation, internet, hobbies/interests

Who helps you cope?

Probe: Family, friends, support groups, counselling staff, social worker,
How do they help?

Probe by providing emotional support, by doing practical/heavy jobs for you, in making decisions, in providing information

How far do you feel in control of what happens to you – in your life?

How far do you feel pressure to be cheerful and upbeat?

Where does this come from? Media, family, staff, friends

How did you find your contacts with doctors/hospitals

When you were first diagnosed

When you were growing up

Since you left school

How far do you trust hospital/health staff?

What's it like at the clinic now?

Check adult or paediatric

What was changing hospitals like?

Probe: as student; moved house

General probes:

Tell me more about …

In what ways was it difficult/a problem …

Anything else about …

Thank you very much for answering the questions.
13.8. INTERVIEWEES' CONSENT FOR PARENTS TO BE INTERVIEWED

Centre Number:

Study Number:

Patient Identification Number for this trial:

Title of Project: Living with transplantation and dialysis as a young adult

Name of Researcher: Helen Lewis

I, the undersigned, voluntarily agree that the researcher Helen Lewis may interview my mother.

I have read and understood the Information Sheet provided. I have been given a full explanation by the investigators of the nature, purpose, location and likely duration of the interview, and of what they will be expected to do. I have been given the opportunity to ask questions on all aspects of the process and have understood the information given as a result.

I understand that all personal data relating to volunteers is held and processed in the strictest confidence, and in accordance with the Data Protection Act (1998). I agree that I will not seek to restrict the use of the results of the study on the understanding that my anonymity is preserved.

Please initial box

1. I understand that my permission to contact my parents/carers is given voluntarily and that I am free to withdraw my consent at any time without giving any reason. □

2. I agree to contact my parent/s or carer and ask them if they are willing to meet the researcher. □

Name of Patient    Date    Signature

Researcher    Date    Signature

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13.9. PARENT/CARER INTERVIEW TOPIC GUIDE

I want to find out more about what it is like for your son/daughter/wife/husband/partner living with kidney failure as a young adult

How do you think it has it affected their life hopes/plans?

How far has it affected getting into college/getting a job?

How has it affected their work/at school/college?

How do you think they manage the practicalities of their illness at work/school/college (especially for dialysis patients)?

Probe: clinic phone calls, getting their blood results, arranging clinic appointments, technology, sterility, supplies at work, disposal of supplies, embarrassment, drink (if on dialysis)

What's it like at home?

Probe: relationships with parents/carers, siblings

How has being ill affected their social and wider family life?

Probe: friends: numbers, closeness; leisure interests; boy friends/girlfriends/potential partners; having children; education; financial situation

How much do you think they talk to people about their illness

Probe: to casual acquaintances; friends at work/college/work; new boyfriend/girlfriend/potential partners; strangers

How much do you think other people/your/their friends/the wider community know about kidney disease?

Probe: media, publicity

How do you feel they feel about their body?

Probe: appearance, height, weight, scars

What do you think that they do to stay as well as possible?

Probe: medication, exercise, eat well, alcohol, smoking

How far do you feel you can trust them to look after themselves properly?

What do you think keeps them sane?

Probe: religion, meditation, internet, hobbies/interests

Who do you think helps them cope?
Probe: family, friends, support groups, counselling staff, social worker,

**What sort of support do you give him/her help?**

Probe: by providing emotional support, by doing practical/heavy jobs for you, in making decisions, in providing information

**How far do you think they feel in control of their lives?**

Probe: independence, autonomy,

**How far do you think they feel pressure to be cheerful and upbeat?**

Where does this come from? Media, family, staff, friends

**How do you think they now find their contacts with doctors/hospitals**

**How far do you trust hospital/health staff?**

Do you ever go to clinic with them?

Check adult or paediatric

If yes, probe: What’s it like at the clinic now?

**What was changing hospitals like?**

Probe: for your son/daughter; for you as a family

**General probes:**

Tell me more about ...

In what ways was it difficult/a problem ...

Anything else about ...

Thank you very much for answering the questions.
13.10. PATIENT CONSENT FORM

Form on university headed paper, 3 copies: 1 each for patient, researcher, hospital notes
Centre Number:
Study Number:
Patient Identification Number for this trial:

Title of Project: Living with transplantation and dialysis as a young adult

Name of Researcher: Helen Lewis

I the undersigned voluntarily agree to take part in the study on living with transplantation and dialysis as a young adult

I have read and understood the Information Sheet provided. I have been given a full explanation by the investigators of the nature, purpose, location and likely duration of the study, and of what I will be expected to do. I have been advised about any discomfort and possible ill-effects on my health and well-being which may result. I have been given the opportunity to ask questions on all aspects of the study and have understood the advice and information given as a result.

I understand that all personal data relating to volunteers is held and processed in the strictest confidence, and in accordance with the Data Protection Act (1998). I agree that I will not seek to restrict the use of the results of the study on the understanding that my anonymity is preserved.

I understand that in the event of my suffering a significant and enduring injury (including illness or disease) as a direct result of my participation in the study, compensation will be paid to me by the University, subject to certain provisos and limitations. The amount of compensation will be appropriate to the nature, severity and persistence of the injury and will, in general terms, be consistent with the amount of damages commonly awarded for similar injury by an English court in cases where the liability has been admitted.

Please initial box

1. I confirm that I have read and understand the information sheet dated ................. (version .............) for the above study and have had the opportunity to ask questions. □

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. □

3. I agree to take part in the above study. □

Name of Patient ___________________________ Date ___________________________ Signature ___________________________

Researcher ___________________________ Date ___________________________ Signature ___________________________

Name of witness ___________________________ Date ___________________________ Signature ___________________________
13.11. LOCAL COLLABORATORS' BRIEFING

Living with transplantation and dialysis, transition to adulthood

Please find enclosed

1. 'N' participants' packs for the above study.

Each envelope contains:

- a letter from the researcher at Surrey University
- a patient information sheet
- a consent form
- a self-completion questionnaire
- a reply paid envelope in which to return the questionnaire and consent form to Surrey University

2. A letter which needs to be finalised locally using Trust headed notepaper. It needs:

- addressing;
- dating;
- insertion of a return date for the questionnaires – one month later than the letter date;
- signing by the local clinician;
- sending out with each of the participants' packs.

3. Each envelope needs an address label from the Trust patient records.

4. A reminder letter to be sent out after 1 month in the envelopes provided.

Many thanks in anticipation of your help in recruiting participants for this study.

Contact details of researcher:

Helen Lewis
Department of Sociology
Surrey University
Guildford
GU2 7XE
01372 725716, m.h.lewis@ntlworld.com
13.12. PILOT RECRUITMENT PROCESS

In each hospital, the lead consultant/Principal Investigator (PI) was asked to nominate a member of his staff to facilitate the necessary administrative work. Participant packs were prepared containing all necessary documentation, needing only the address of the patients from the hospital database, and a letter signed by the PI. Invitations to participate in the study were sent out on notepaper carrying the logo of University of Surrey and that of the hospital with equal prominence.

Over a period of six weeks, hospital staff carried out a search of their electronic patient database, identified patients aged 16-30 (124) and created patient-unique letters (124). These were signed by hand in real time, by the PI. On hospital premises, the researcher put these into pre-prepared participants' packs, each containing: a numbered questionnaire, a patient information sheet, a consent form, a letter on invitation to participate from me, and a reply paid envelope. These packs were then addressed by the researcher under supervision.

There were many delays in this process, as the work involved was additional to the normal workload of the staff involved, and as patient databases were used by renal unit staff, but owned by the hospitals' IT departments. The latter meant it was difficult to identify eligible patients. This process proved challenging and four more pilots were conducted in local hospitals to explore how to manage gaining support from geographically dispersed, and differently resourced renal units.

13.13. MAIN DATA COLLECTION PROCESS

The full survey aimed to obtain reasonably representative data from the eligible ERF patient population. The participants packs were sent to all patients with date of birth January 1976 to December 1990 inclusive (ie aged 16-30 years inclusive on 31.12.2006), in hospitals in different parts of the England. This was conducted hospital by hospital, as and when R&D approval was received over the next year.

Hospitals facilitated the mail out to a different extent, depending on staffing resources. These ranged from:

- hospitals (3): despatched pre-prepared questionnaire packs posted by the researcher to the leading hospital consultant at the unit. They included a covering letter signed by the lead consultant;
- hospitals (2): the researcher travelled to the hospitals with questionnaire packs, accessed patients' record systems on site and addressed the letters by hand, keeping no record of contact details, and
- hospitals (2) where the questionnaire was sent out only to transplant patients. One of these hospitals didn't have any dialysis patients.

In total, 931 survey questionnaires were sent to all eligible patients treated at 12 adult tertiary level renal units across England, and two children's units, one in the north and one in the south, between spring 2006 and spring 2007.

Reminder letters and questionnaires were sent to non-respondents at between one and two months after the initial mail out. The gap between original mail out and reminders varied according to local advice from hospital staff and time of year, public holidays etc. Thus, in most cases the survey distribution involved a minimum of 2
hospital visits, one to send out the questionnaires and a second, 4-6 weeks later, to send out the reminders.

Two pilot questionnaire responses from non-participating hospital patients met the selection criteria in that the patients were over 16 and under 30 years at the end of 2006. These were included for analysis in the final data set (N=296, response rate 32%).
13.14. RATIONALE FOR SELECTION OF DATA SUBSET

Age under 16 years at onset of RRT

It was decided to divide the data into 2 groups by the age of beginning RRT and age of beginning RRT 'under sixteen years' was selected as the most appropriate age for the division.

- 16 is the age in which most school pupils do their GCSE examinations, in which passes at Grade C and over, especially in English and Mathematics, remain important for entering further education and/or employment.
- 16 is the normal age of transfer from children's renal units to adult units across the country, although practice varies if children are still at school.
- Puberty is delayed in many chronic renal failure patients as early growth is delayed and body mass as well as age and inherited characteristic are amongst the factors that influence the age at which puberty occurs.
- Delayed puberty, as well as ill health, affects young adults' capacity to engage fully in the normal activities of the peers.
- Some children with acute onset of ERF at 16 are admitted directly into adult units without passing through a paediatric unit.

Since incidence of ERF increases with age, particularly in the years leading up to puberty, choice of a younger age group, whilst desirable, led to insufficient numbers in the early group. Puberty is a process which begins at 10-11 years and which may not be complete until 15 or 16 in healthy individuals, but maybe delayed by ERF.

Dividing the data set in this way resulted in a 2:3 split in the data (110 RRT<16 years: 182 RRT >=16 years, with 4 non-respondents), there being more questionnaire respondents with RRT aged 16 and over than with RRT aged under 16.

Other ages that were considered were age RRT under age 19 years and age RRT under 22 years. The former would allow a more even split of the data and a larger sample (156 patients under 19 years: 136 patients 19 years and older), and is related to the 'age of majority' (18 years) in present day society, however it relates less well to the factors listed above. 'Age under 22' is related to older ideas about 'coming of age' and the end of traditional formal higher education, and would have offered an even larger sample with associated greater potential for finding statistically significant associations between variables. However the 'coming of age' at 21 is less relevant to the young people of the 21st century, where transition to adulthood is prolonged compared with 50 years ago.

Comparison of sample sizes by selection according to age of beginning RRT

<table>
<thead>
<tr>
<th>Age RRT began</th>
<th>Sample size N Under age (% 296)</th>
<th>Sample size N At or over age (% 296)</th>
</tr>
</thead>
<tbody>
<tr>
<td>16 years</td>
<td>110 (37.2%)</td>
<td>182 (61.5%)</td>
</tr>
<tr>
<td>19 years</td>
<td>156 (53.4%)</td>
<td>136 (46.6%)</td>
</tr>
<tr>
<td>22 years</td>
<td>204 (69.9%)</td>
<td>88 (30.1%)</td>
</tr>
</tbody>
</table>
Respondents aged 23 years and older at the end of 2006 (designated adult)
In order to explore how far respondents had accomplished transition into adulthood, it was decided to further limit detailed analysis to only those respondents who could reasonably have been assumed to have achieved adult status had they not been ill.

Age 23 years at the end of 2006 (N= 224, 75.7%) was chosen as the age at which it can be argued most young adults will have completed their full time education, found a job and might have left the parental home (the latter being perhaps a less reliable indicator in the 21st century with house prices rising steeply over the years 1990-2007). Divisions considered and resultant sample sizes are illustrated below.

Comparison of sample sizes by age at end of 2006

<table>
<thead>
<tr>
<th>Age end 2006</th>
<th>Sample size N Under age (% 296)</th>
<th>Sample size N At or over age (% 296)</th>
</tr>
</thead>
<tbody>
<tr>
<td>22 years</td>
<td>64 (21.6%)</td>
<td>232 (78.4%)</td>
</tr>
<tr>
<td>23 years</td>
<td>72 (24.3%)</td>
<td>224 (75.7%)</td>
</tr>
<tr>
<td>26 years</td>
<td>124 (41.9%)</td>
<td>172 (58.1%)</td>
</tr>
</tbody>
</table>

Respondents age 23 or older and in stable health
It was further decided, after much deliberation, to include in the analysis only those 23 years and older whose current modality had been stable for more than 2 years (N=146, 49.3% of N=296). This was to eliminate, for the most part, those respondents who might have recently had a surgical intervention (related to transplantation or dialysis) and/or begun a course of drug treatment with serious/debilitating side effects. This also eliminated those respondents who had experienced recent transplant failure and begun dialysis for the first or nth time. However, this reduced the sample size considerably (by 35%) and therefore greatly reduced the possibility of finding statistically significant associations between variables. In practice this made no difference to the significance of findings related to salient markers of adulthood used, which are described below.

The selected subgroup of respondents is characterised below. It is, as a whole, as well and stable as might be expected given the chronic and complex nature of ERF. No controls for other co-morbidities were made.

Distribution of selected subset of respondents aged 23 or over with stable health by age group onset RRT

<table>
<thead>
<tr>
<th>Respondents aged 23 or older (31.12.06) in stable health</th>
<th>N</th>
<th>% 146</th>
<th>% 296</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early onset RRT (under 16 years)</td>
<td>57</td>
<td>39.0</td>
<td>19.3</td>
</tr>
<tr>
<td>Late onset RRT (aged 16 and over)</td>
<td>89</td>
<td>61.0</td>
<td>30.1</td>
</tr>
<tr>
<td>Totals</td>
<td>146</td>
<td>100</td>
<td>49.3</td>
</tr>
</tbody>
</table>
### Characteristics of respondents with stable health and aged 23 or over by age of onset RRT

<table>
<thead>
<tr>
<th>Respondents aged 23 or older and in stable health</th>
<th>Early onset N = 57</th>
<th>Late onset N = 89</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (mean) 31.12.06</td>
<td>26.5</td>
<td>27.7</td>
</tr>
<tr>
<td>Height mean in cm</td>
<td>163</td>
<td>171</td>
</tr>
<tr>
<td>Weight mean in kg</td>
<td>65</td>
<td>69</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>47.4%</td>
<td>52.8%</td>
</tr>
<tr>
<td>Female</td>
<td>52.6%</td>
<td>47.2%</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>82.1%</td>
<td>77.5%</td>
</tr>
<tr>
<td>Black</td>
<td>3.6%</td>
<td>6.7%</td>
</tr>
<tr>
<td>Asian</td>
<td>12.5%</td>
<td>7.9%</td>
</tr>
<tr>
<td>Other</td>
<td>1.8%</td>
<td>7.9%</td>
</tr>
<tr>
<td>Current RRT</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transplant</td>
<td>75.4%</td>
<td>78.7%</td>
</tr>
<tr>
<td>Dialysis</td>
<td>24.6%</td>
<td>21.3%</td>
</tr>
<tr>
<td>Age onset RRT (mean)</td>
<td>10.16</td>
<td>20.91</td>
</tr>
<tr>
<td>Age onset RRT (median)</td>
<td>10.00</td>
<td>21.0</td>
</tr>
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</table>
Table 1 UK paediatric renal transplant recipients' age at time of graft, 1999-2004

<table>
<thead>
<tr>
<th>Recipients' age</th>
<th>Year of graft</th>
<th>1999</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
<th>2004</th>
<th>Total</th>
</tr>
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<tbody>
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<td>2</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>1</td>
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<td>7</td>
<td>4</td>
<td>3</td>
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<td>4</td>
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<tr>
<td>3</td>
<td></td>
<td>8</td>
<td>6</td>
<td>5</td>
<td>7</td>
<td>1</td>
<td>5</td>
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<tr>
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<td>6</td>
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<td>7</td>
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<td>3</td>
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<td>3</td>
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<td>2</td>
<td>7</td>
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<td></td>
<td>9</td>
<td>5</td>
<td>5</td>
<td>7</td>
<td>2</td>
<td>5</td>
<td>33</td>
</tr>
<tr>
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<td>10</td>
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<td>41</td>
</tr>
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<td>9</td>
<td>7</td>
<td>10</td>
<td>10</td>
<td>13</td>
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<tr>
<td>12</td>
<td></td>
<td>9</td>
<td>8</td>
<td>11</td>
<td>9</td>
<td>11</td>
<td>5</td>
<td>56</td>
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<tr>
<td>13</td>
<td></td>
<td>12</td>
<td>9</td>
<td>9</td>
<td>6</td>
<td>12</td>
<td>5</td>
<td>53</td>
</tr>
<tr>
<td>14</td>
<td></td>
<td>11</td>
<td>8</td>
<td>12</td>
<td>15</td>
<td>9</td>
<td>11</td>
<td>66</td>
</tr>
<tr>
<td>15</td>
<td></td>
<td>17</td>
<td>8</td>
<td>11</td>
<td>9</td>
<td>18</td>
<td>6</td>
<td>69</td>
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<tr>
<td>16</td>
<td></td>
<td>11</td>
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<td>20</td>
<td>14</td>
<td>15</td>
<td>12</td>
<td>89</td>
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<td>17</td>
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<td>20</td>
<td>15</td>
<td>22</td>
<td>16</td>
<td>12</td>
<td>15</td>
<td>100</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td>139</td>
<td>128</td>
<td>135</td>
<td>123</td>
<td>130</td>
<td>114</td>
<td>769</td>
</tr>
</tbody>
</table>

Personal communication from UK Transplant, 22.12.04
Table 2 Comparison of haemodialysis and peritoneal dialysis for children and parents

<table>
<thead>
<tr>
<th>RRT</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Haemodialysis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Children</strong></td>
<td>Free on non HD days</td>
<td>Time-consuming</td>
</tr>
<tr>
<td></td>
<td>Peer support</td>
<td>Physically restricting</td>
</tr>
<tr>
<td></td>
<td>Independence from parents</td>
<td>Disrupts education/social life</td>
</tr>
<tr>
<td><strong>Parents</strong></td>
<td>Freedom from treatment</td>
<td>Burden of travel</td>
</tr>
<tr>
<td></td>
<td>Close support from Unit</td>
<td>Financial cost</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Disrupts family life</td>
</tr>
<tr>
<td><strong>Peritoneal dialysis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Children</strong></td>
<td>Advantages for infants</td>
<td>Body image</td>
</tr>
<tr>
<td></td>
<td>Education full-time</td>
<td>Pressure of treatment</td>
</tr>
<tr>
<td></td>
<td>More social time</td>
<td>Complications, hospital admissions</td>
</tr>
<tr>
<td></td>
<td>Greater independence</td>
<td></td>
</tr>
<tr>
<td><strong>Parents</strong></td>
<td>More flexibility</td>
<td>Pressure of treatment</td>
</tr>
<tr>
<td></td>
<td>Holidays</td>
<td>'Burnout'</td>
</tr>
<tr>
<td></td>
<td>Maintain caring role</td>
<td>Ambivalence in role</td>
</tr>
</tbody>
</table>

Adapted from Reynolds and Postlethwaite (Reynolds & Postlethwaite, 1996, Supplement 1, Table 1, S550)
Table 3 Characteristics of participating NHS hospitals

<table>
<thead>
<tr>
<th>Hospital</th>
<th>Hospital Trust</th>
<th>Transplant Centre</th>
<th>Age range treated</th>
<th>Took part</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>A city in the midlands</td>
<td>Yes</td>
<td>Adult and paediatric</td>
<td>✓</td>
</tr>
<tr>
<td>B withdrew</td>
<td>A city in the midlands</td>
<td>Yes</td>
<td>Adult, no paediatric</td>
<td>✗</td>
</tr>
<tr>
<td>C</td>
<td>A city in the west</td>
<td>Yes</td>
<td>Adult and paediatric</td>
<td>✓</td>
</tr>
<tr>
<td>D</td>
<td>A city in the midlands</td>
<td>Yes</td>
<td>Adult, no paediatric</td>
<td>✓</td>
</tr>
<tr>
<td>E</td>
<td>A city in the south east</td>
<td>Yes</td>
<td>Paediatric, no adult</td>
<td>✓</td>
</tr>
<tr>
<td>F withdrew</td>
<td>A city in the south east</td>
<td>No</td>
<td>Adult and paediatric</td>
<td>✗</td>
</tr>
<tr>
<td>G merged with L</td>
<td>A city in the south east</td>
<td>Yes</td>
<td>Adult, no paediatric</td>
<td>✓</td>
</tr>
<tr>
<td>H</td>
<td>A city in the south east</td>
<td>No</td>
<td>Adult, no paediatric</td>
<td>✓</td>
</tr>
<tr>
<td>I</td>
<td>A city in the south east</td>
<td>Yes</td>
<td>Adult, no paediatric</td>
<td>✓</td>
</tr>
<tr>
<td>J</td>
<td>A city in the south east</td>
<td>Yes</td>
<td>Adult, no paediatric</td>
<td>✓</td>
</tr>
<tr>
<td>K</td>
<td>A city in the south east</td>
<td>Yes</td>
<td>Adult, no paediatric</td>
<td>✓</td>
</tr>
<tr>
<td>L merged with G</td>
<td>A city in the south east</td>
<td>Yes</td>
<td>Adult, no paediatric</td>
<td>✓</td>
</tr>
<tr>
<td>M and MC</td>
<td>A city in the north</td>
<td>Yes</td>
<td>Adult and paediatric</td>
<td>✓</td>
</tr>
<tr>
<td>N</td>
<td>A city in the midlands</td>
<td>Yes</td>
<td>Adult, no paediatric</td>
<td>✓</td>
</tr>
<tr>
<td>O</td>
<td>A city in the north</td>
<td>Yes</td>
<td>Adult, no paediatric</td>
<td>✓</td>
</tr>
<tr>
<td>P replacement</td>
<td>A city in the south east</td>
<td>No</td>
<td>Adult, no paediatric</td>
<td>✓</td>
</tr>
</tbody>
</table>
Table 4 Significance of association between registered disabled and age beginning RRT, subset of survey respondents' data

<table>
<thead>
<tr>
<th>Registered as disabled</th>
<th>Age now 23 or older &amp; stable</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>% Under 16</td>
<td>% 16 and over</td>
<td></td>
</tr>
<tr>
<td>Registered</td>
<td>30.0</td>
<td>20.2</td>
<td>32</td>
</tr>
<tr>
<td>Not registered</td>
<td>70.0</td>
<td>79.8</td>
<td>102</td>
</tr>
<tr>
<td>Totals</td>
<td>50</td>
<td>84</td>
<td>134</td>
</tr>
</tbody>
</table>

χ² = 1.64, df = 1, p = 0.20
(Survey Q 5g)

Table 5 Interviewees' disability status and modality, survey data

<table>
<thead>
<tr>
<th>Disability status</th>
<th>Transplant N</th>
<th>Dialysis N</th>
<th>Total N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registered as disabled</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Registered</td>
<td>6</td>
<td>4</td>
<td>10</td>
</tr>
<tr>
<td>Not registered</td>
<td>18</td>
<td>6</td>
<td>24</td>
</tr>
<tr>
<td>Totals</td>
<td>24</td>
<td>10</td>
<td>34</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>See self as having disability?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>3</td>
</tr>
<tr>
<td>No</td>
<td>13</td>
</tr>
<tr>
<td>Sometimes</td>
<td>11</td>
</tr>
<tr>
<td>Totals</td>
<td>27</td>
</tr>
</tbody>
</table>

(Survey Q 5g)

---

21 30% survey respondents were registered as having a disability, 22% survey respondents saw themselves as 'having a disability', and 33% survey respondents saw themselves as 'sometimes having a disability' (data not tabled here).
<table>
<thead>
<tr>
<th>Interviewee's name</th>
<th>Parent</th>
<th>Face to Face/telephone</th>
<th>Occupation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alice</td>
<td>Mother</td>
<td>F to F</td>
<td>Retail manager</td>
</tr>
<tr>
<td>Amy</td>
<td>Father</td>
<td>T</td>
<td>Adult trainer</td>
</tr>
<tr>
<td>Anna</td>
<td>Mother</td>
<td>F to F</td>
<td>Not employed</td>
</tr>
<tr>
<td>Carmen</td>
<td>Mother</td>
<td>T</td>
<td>Teacher</td>
</tr>
<tr>
<td>Daniel</td>
<td>Mother</td>
<td>F to F</td>
<td>Teacher</td>
</tr>
<tr>
<td></td>
<td>Father</td>
<td>F to F</td>
<td>Lecturer</td>
</tr>
<tr>
<td>George</td>
<td>Mother</td>
<td>F to F</td>
<td>Public sector</td>
</tr>
<tr>
<td>Henry</td>
<td>Mother</td>
<td>F to F</td>
<td>Lecturer</td>
</tr>
<tr>
<td>James</td>
<td>Mother</td>
<td>F to F</td>
<td>PT school helper</td>
</tr>
<tr>
<td>Jerry</td>
<td>Mother</td>
<td>T</td>
<td>Youth work</td>
</tr>
<tr>
<td>Jude</td>
<td>Mother</td>
<td>T</td>
<td>Nurse</td>
</tr>
<tr>
<td>Kelly</td>
<td>Mother</td>
<td>T</td>
<td>Classroom assistant</td>
</tr>
<tr>
<td>Luc</td>
<td>Mother</td>
<td>T</td>
<td>Not known</td>
</tr>
<tr>
<td>Luther</td>
<td>Mother</td>
<td>T</td>
<td>School dinner helper</td>
</tr>
<tr>
<td>Marc</td>
<td>Mother</td>
<td>T</td>
<td>Administration</td>
</tr>
<tr>
<td>Marian</td>
<td>Mother</td>
<td>T</td>
<td>School librarian</td>
</tr>
<tr>
<td>Oliver</td>
<td>Mother</td>
<td>F to F</td>
<td>Not employed</td>
</tr>
<tr>
<td>Tanya</td>
<td>Mother</td>
<td>T</td>
<td>Not known</td>
</tr>
<tr>
<td>Tristram</td>
<td>Mother</td>
<td>F to F</td>
<td>Not employed</td>
</tr>
<tr>
<td>Unnamed pilot</td>
<td>Mother</td>
<td>F to F</td>
<td>Teacher</td>
</tr>
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</table>
Table 7 Interviewees' age, age RRT, modality and experience of transplant loss, by age RRT, self reported

<table>
<thead>
<tr>
<th>Name</th>
<th>Age 2006</th>
<th>Age RRT</th>
<th>RRT Now</th>
<th>Duration</th>
<th>Prev Tx</th>
<th>Transplant history</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sara</td>
<td>27</td>
<td>2</td>
<td>Tx</td>
<td>&lt;1 yr</td>
<td>yes</td>
<td>2 Tx: 1980 for 24 years; 2005 ongoing</td>
</tr>
<tr>
<td>Satish</td>
<td>28</td>
<td>2</td>
<td>HD</td>
<td>5-10 yrs</td>
<td>yes</td>
<td>3 Tx: 1980; 1983; 1986 for 14 yrs</td>
</tr>
<tr>
<td>Debra</td>
<td>27</td>
<td>4</td>
<td>Tx</td>
<td>&gt; 10 yrs</td>
<td>yes</td>
<td>2 Tx: 1984 for 5 yrs; 1989 ongoing</td>
</tr>
<tr>
<td>Kelly</td>
<td>17</td>
<td>4</td>
<td>HD</td>
<td>2-3 yrs</td>
<td>yes</td>
<td>1 Tx: 1995 for 9.5 yrs</td>
</tr>
<tr>
<td>Ben</td>
<td>29</td>
<td>5</td>
<td>Tx</td>
<td>3-4 yrs</td>
<td>yes</td>
<td>3 Tx: for 1, 5, 9 years; 2002 ongoing</td>
</tr>
<tr>
<td>Tristram</td>
<td>29</td>
<td>5</td>
<td>HD</td>
<td>5-10 yrs</td>
<td>yes</td>
<td>2 Tx: 1982 for 1.5 years; 1984 for 17 yrs</td>
</tr>
<tr>
<td>Luther</td>
<td>27</td>
<td>6</td>
<td>HD</td>
<td>5-10 yrs</td>
<td>yes</td>
<td>2 Tx: 1986 for 6 months; 1988 for 8 yrs</td>
</tr>
<tr>
<td>Amy</td>
<td>24</td>
<td>7</td>
<td>Tx</td>
<td>4-5 yrs</td>
<td>yes</td>
<td>3 Tx: 1990, 0 hrs; 1990, 4 yrs; 2001 ongoing</td>
</tr>
<tr>
<td>Edward</td>
<td>30</td>
<td>7</td>
<td>HD</td>
<td>1-2 yrs</td>
<td>yes</td>
<td>2 Tx: one for 6 months; 1986 for 16 yrs</td>
</tr>
<tr>
<td>Jerry</td>
<td>25</td>
<td>7</td>
<td>Tx</td>
<td>2-3 yrs</td>
<td>yes</td>
<td>2 Tx: 1993 for 10 years; 2003 ongoing</td>
</tr>
<tr>
<td>Kieren</td>
<td>29</td>
<td>7</td>
<td>Tx</td>
<td>2-3 yrs</td>
<td>yes</td>
<td>3 Tx: 1985, 15 yrs; 1984, 1 mth; 2004 ongoing</td>
</tr>
<tr>
<td>Oliver</td>
<td>26</td>
<td>7</td>
<td>Tx</td>
<td>5-10 yrs</td>
<td>yes</td>
<td>2 Tx: 1987, 1999 ongoing</td>
</tr>
<tr>
<td>Cecile</td>
<td>26</td>
<td>8</td>
<td>Tx</td>
<td>&gt; 10 yrs</td>
<td>no</td>
<td>1Tx: 1988, interview data</td>
</tr>
<tr>
<td>Jon</td>
<td>27</td>
<td>8</td>
<td>HD</td>
<td>5-10 yrs</td>
<td>yes</td>
<td>2 Tx: 1988 for 8 years; 1997 for 4 yrs</td>
</tr>
<tr>
<td>Alice</td>
<td>24</td>
<td>9</td>
<td>PD</td>
<td>5-10 yrs</td>
<td>yes</td>
<td>2 Tx: 4/72 for 2 hours, 7/92 for 7 yrs</td>
</tr>
<tr>
<td>Eugene</td>
<td>27</td>
<td>9</td>
<td>Tx</td>
<td>&gt; 10 yrs</td>
<td>no</td>
<td>1 Tx: 1988 ongoing</td>
</tr>
<tr>
<td>Lucy</td>
<td>27</td>
<td>9</td>
<td>Tx</td>
<td>&gt; 10 yrs</td>
<td>no</td>
<td>1 Tx: 1988 ongoing</td>
</tr>
<tr>
<td>Lyn</td>
<td>19</td>
<td>9</td>
<td>PD</td>
<td>2-3 yrs</td>
<td>yes</td>
<td>1 Tx: 1998 for 5 years</td>
</tr>
<tr>
<td>Petra</td>
<td>30</td>
<td>9</td>
<td>Tx</td>
<td>4-5 yrs</td>
<td>yes</td>
<td>2 Tx: 1986 for 12 years; 2002 ongoing</td>
</tr>
<tr>
<td>Daniel</td>
<td>27</td>
<td>10</td>
<td>Tx</td>
<td>5-10 yrs</td>
<td>yes</td>
<td>3 Tx: 1989; 97; 98 now failing</td>
</tr>
<tr>
<td>Jude</td>
<td>22</td>
<td>10</td>
<td>PD</td>
<td>3-4 yrs</td>
<td>yes</td>
<td>1 Tx: 1997 for 6 years</td>
</tr>
<tr>
<td>Marc</td>
<td>30</td>
<td>10</td>
<td>Tx</td>
<td>&gt; 10 yrs</td>
<td>no</td>
<td>1 Tx: 1987 ongoing</td>
</tr>
</tbody>
</table>

Age onset RRT 11 and over regarded as pubertal and post-pubertal (N=18)

<table>
<thead>
<tr>
<th>Name</th>
<th>Age 2006</th>
<th>Age RRT</th>
<th>RRT Now</th>
<th>Duration</th>
<th>Prev Tx</th>
<th>Transplant history</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tanya</td>
<td>28</td>
<td>11</td>
<td>Tx</td>
<td>&gt; 10 yrs</td>
<td>yes</td>
<td>2 Tx: 1990, 1991 ongoing</td>
</tr>
<tr>
<td>Anna</td>
<td>28</td>
<td>12</td>
<td>Tx</td>
<td>&gt; 10 yrs</td>
<td>no</td>
<td>1 Tx: ongoing</td>
</tr>
<tr>
<td>James</td>
<td>16</td>
<td>12</td>
<td>Tx</td>
<td>3-4 yrs</td>
<td>yes</td>
<td>2 Tx: 2003 for 11 days; 2003 ongoing</td>
</tr>
<tr>
<td>Matt</td>
<td>24</td>
<td>14</td>
<td>Tx</td>
<td>&gt; 10 yrs</td>
<td>no</td>
<td>1 Tx: 1997 ongoing</td>
</tr>
<tr>
<td>Carmen</td>
<td>24</td>
<td>15</td>
<td>Tx</td>
<td>5-10 yrs</td>
<td>yes</td>
<td>2 Tx: 8/1997 for 2 months, 8/2001 ongoing</td>
</tr>
<tr>
<td>Mario</td>
<td>28</td>
<td>15</td>
<td>Tx</td>
<td>4-5 yrs</td>
<td>yes</td>
<td>1 Tx: 95 for 1.5 years, 2002 ongoing</td>
</tr>
<tr>
<td>Wayne</td>
<td>20</td>
<td>15</td>
<td>Tx</td>
<td>4-5 yrs</td>
<td>no</td>
<td>1 Tx: 2002 ongoing</td>
</tr>
<tr>
<td>Marian</td>
<td>19</td>
<td>16</td>
<td>Tx</td>
<td>2-3 yrs</td>
<td>no</td>
<td>1 Tx: 2004 ongoing</td>
</tr>
<tr>
<td>Millie</td>
<td>26</td>
<td>16</td>
<td>Tx</td>
<td>5-10 yrs</td>
<td>no</td>
<td>1 Tx: 2000 ongoing</td>
</tr>
<tr>
<td>Raj</td>
<td>22</td>
<td>16</td>
<td>Tx</td>
<td>&lt;1 yr</td>
<td>no</td>
<td>1 Tx: 2006 ongoing</td>
</tr>
<tr>
<td>Ajay</td>
<td>28</td>
<td>17</td>
<td>Tx</td>
<td>&gt; 10 yrs</td>
<td>no</td>
<td>1 Tx: 1995 ongoing</td>
</tr>
<tr>
<td>Hanna</td>
<td>18</td>
<td>17</td>
<td>HD</td>
<td>1-2 yrs</td>
<td>no</td>
<td>Never transplanted</td>
</tr>
<tr>
<td>Samuel</td>
<td>28</td>
<td>17</td>
<td>HD</td>
<td>5-10 yrs</td>
<td>yes</td>
<td>1 Tx: 1995 for 4 years</td>
</tr>
<tr>
<td>George</td>
<td>29</td>
<td>18</td>
<td>Tx</td>
<td>&lt;1 yr</td>
<td>yes</td>
<td>2 Tx: 1998, 2005 ongoing</td>
</tr>
<tr>
<td>Luc</td>
<td>24</td>
<td>18</td>
<td>Tx</td>
<td>3-4 yrs</td>
<td>no</td>
<td>1 Tx: 2003 ongoing</td>
</tr>
<tr>
<td>Henry</td>
<td>30</td>
<td>19</td>
<td>Tx</td>
<td>5-10 yrs</td>
<td>no</td>
<td>1 Tx: 1997 ongoing</td>
</tr>
<tr>
<td>Laura</td>
<td>30</td>
<td>19</td>
<td>Tx</td>
<td>5-10 yrs</td>
<td>no</td>
<td>1 Tx: 1997 ongoing</td>
</tr>
<tr>
<td>Gus</td>
<td>25</td>
<td>22</td>
<td>PD</td>
<td>1-2 yrs</td>
<td>no</td>
<td>Never transplanted</td>
</tr>
</tbody>
</table>
Table 8 Media representation of ERF, all responses

<table>
<thead>
<tr>
<th></th>
<th>N Respondents mentioning coded items</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What do you think and feel about the way people with kidney disease are written about in newspapers and seen in TV programmes?</strong></td>
<td>260</td>
<td></td>
</tr>
<tr>
<td>Generally trivialising</td>
<td>5</td>
<td>1.9</td>
</tr>
<tr>
<td>Doesn't show complexity and/or suffering</td>
<td>60</td>
<td>23.1</td>
</tr>
<tr>
<td>Make it look too easy</td>
<td>38</td>
<td>14.6</td>
</tr>
<tr>
<td>Not accurate and/or realistic</td>
<td>28</td>
<td>10.8</td>
</tr>
<tr>
<td>Diminishes me as a person</td>
<td>4</td>
<td>1.5</td>
</tr>
<tr>
<td>Upsets and/or depresses me</td>
<td>10</td>
<td>3.8</td>
</tr>
<tr>
<td>Offers real patient no voice</td>
<td>2</td>
<td>0.8</td>
</tr>
<tr>
<td>Over-dramatised</td>
<td>3</td>
<td>1.2</td>
</tr>
<tr>
<td>Too much focus on donor and not on patient</td>
<td>4</td>
<td>1.5</td>
</tr>
<tr>
<td><strong>Total: poor representation</strong></td>
<td>154</td>
<td>59.2</td>
</tr>
<tr>
<td>Show it as a death sentence</td>
<td>20</td>
<td>7.7</td>
</tr>
<tr>
<td>Too much focus on suffering, when it is manageable</td>
<td>19</td>
<td>7.3</td>
</tr>
<tr>
<td>Annoys me (often with too much focus on suffering)</td>
<td>6</td>
<td>2.3</td>
</tr>
<tr>
<td><strong>Total: generally too much about suffering</strong></td>
<td>45</td>
<td>17.3</td>
</tr>
<tr>
<td>Not much coverage/information (excl below)</td>
<td>24</td>
<td>9.2</td>
</tr>
<tr>
<td>I haven't see it/read anything</td>
<td>33</td>
<td>12.7</td>
</tr>
<tr>
<td>Not enough coverage</td>
<td>25</td>
<td>9.6</td>
</tr>
<tr>
<td>Not enough coverage of need for donation</td>
<td>2</td>
<td>0.7</td>
</tr>
<tr>
<td><strong>Total: too little coverage</strong></td>
<td>84</td>
<td>32.2</td>
</tr>
<tr>
<td>Good/OK representation general (excl below)</td>
<td>18</td>
<td>6.9</td>
</tr>
<tr>
<td>Positive messages help me</td>
<td>8</td>
<td>3.1</td>
</tr>
<tr>
<td>Raises awareness general</td>
<td>5</td>
<td>1.9</td>
</tr>
<tr>
<td>Good education for others</td>
<td>10</td>
<td>3.8</td>
</tr>
<tr>
<td>Gets donation publicity</td>
<td>4</td>
<td>1.5</td>
</tr>
<tr>
<td>I can relate to it</td>
<td>3</td>
<td>1.2</td>
</tr>
<tr>
<td><strong>Total: good coverage</strong></td>
<td>48</td>
<td>18.4</td>
</tr>
<tr>
<td>I don't concern myself with it/doesn't bother me</td>
<td>9</td>
<td>3.5</td>
</tr>
<tr>
<td>Not sure/don't know what to think</td>
<td>11</td>
<td>4.2</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
<td>1.9</td>
</tr>
<tr>
<td><strong>Total: other</strong></td>
<td>25</td>
<td>9.6</td>
</tr>
</tbody>
</table>

(Survey Q11a)

---

22 Survey questions 11a, b and c were open text. Responses presented in Table 9, Table 11, and Table 13, were managed using Max QDA and coded by the author.
<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>RRT</th>
<th>What do you think and feel about the way people with kidney disease are written about in the newspapers and seen in TV programmes?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ajay</td>
<td>2</td>
<td>RRT</td>
<td>I don't find it very true. There is not much focus on what the patient actually goes through emotionally, how their physical appearance changes, psycho...</td>
</tr>
<tr>
<td>Alice</td>
<td>2</td>
<td></td>
<td>On TV I just see all these 'normal' people &amp; I don't see people doing stuff. For example on singers, or TV people or Big brother are all normal. What happened to thinking about how interesting the life of a kidney patient is?</td>
</tr>
<tr>
<td>Amy</td>
<td>4</td>
<td></td>
<td>Inaccurate in that people think that once you have a transplant you are fixed for life and you will never need dialysis again. This needs expansion.</td>
</tr>
<tr>
<td>Anna</td>
<td>4</td>
<td></td>
<td>That it's a 'disease' rather than in most cases, a manageable condition either through dialysis or transplantation. Especially people who've had successful transplants are portrayed as 'ill' or suffering people</td>
</tr>
<tr>
<td>Ben</td>
<td>5</td>
<td></td>
<td>Transplantation too often portrayed as 'plug and play' – unrealistic</td>
</tr>
<tr>
<td>Carmen</td>
<td>5</td>
<td></td>
<td>It's not really been documented</td>
</tr>
<tr>
<td>Cecile</td>
<td>6</td>
<td></td>
<td>No response</td>
</tr>
<tr>
<td>Daniel</td>
<td>7</td>
<td></td>
<td>Not sure. Usually the focus isn't the kidney but the person - TV dramas and all that</td>
</tr>
<tr>
<td>Debra</td>
<td>7</td>
<td></td>
<td>No response</td>
</tr>
<tr>
<td>Edward</td>
<td>7</td>
<td></td>
<td>Needs to be a better coordinated approach across the country - more information and proactive raising issues</td>
</tr>
<tr>
<td>Eugene</td>
<td>7</td>
<td></td>
<td>Not enough on TV about it to comment</td>
</tr>
<tr>
<td>George</td>
<td>7</td>
<td></td>
<td>Comes over as a simple problem, with an easy fix solution, with little mention of how ill some people are.</td>
</tr>
<tr>
<td>Gus</td>
<td>8</td>
<td></td>
<td>Kidney disease is not seen as a serious health issue as much as it should be. The media portrays an easy 'cure' of dialysis and transplants which last forever. Psychological, diet and lifestyle effects are rarely mentioned.</td>
</tr>
<tr>
<td>Hanna</td>
<td>8</td>
<td></td>
<td>Not enough portrayal at all! Kidney disease is a major disease, yet about 50% of the population don't know what dialysis is! I think there should be more information to educate the public about this disease, so they are more aware of it.</td>
</tr>
<tr>
<td>Henry</td>
<td>9</td>
<td></td>
<td>Too optimistic. Often focus on the successes, never the huge impact of the condition on all aspects of one's life and family/carers, or time frustrations of hospital environment</td>
</tr>
<tr>
<td>James</td>
<td>9</td>
<td></td>
<td>I haven't seen any programmes or seen anything in the newspaper</td>
</tr>
<tr>
<td>Jerry</td>
<td>9</td>
<td></td>
<td>Never see any</td>
</tr>
<tr>
<td>Jon</td>
<td>9</td>
<td></td>
<td>No response</td>
</tr>
<tr>
<td>Jude</td>
<td>9</td>
<td></td>
<td>They make it sound as if it's all doom and gloom</td>
</tr>
<tr>
<td>Kelly</td>
<td>10</td>
<td></td>
<td>TV angry, everything goes well. Never seem to get told of the pros and cons of transplantation, effects of dialysis on family. Portrayed through rose-coloured glasses</td>
</tr>
<tr>
<td>Kieron</td>
<td>10</td>
<td></td>
<td>They don't have enough information, plus TV portrays kidney failure in wrong way as if it is easy. You can get a transplant, no problem</td>
</tr>
<tr>
<td>Name</td>
<td>Age</td>
<td>What do you think and feel about the way people with kidney disease are written about in the newspapers and seen in TV programmes?</td>
<td></td>
</tr>
<tr>
<td>--------</td>
<td>-----</td>
<td>-------------------------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Laura</td>
<td>10</td>
<td>No response</td>
<td></td>
</tr>
<tr>
<td>Luc</td>
<td>11</td>
<td>I think we get overshadowed somewhat by heart disease and liver failure. They're important of course, but I think most people would think, 'Oh I've got a spare if one goes wrong, so why worry about renal failure'.</td>
<td></td>
</tr>
<tr>
<td>Lucy</td>
<td>12</td>
<td>No response</td>
<td></td>
</tr>
<tr>
<td>Luther</td>
<td>12</td>
<td>They don't tell it how it really is in real life, well in my life</td>
<td></td>
</tr>
<tr>
<td>Lyn</td>
<td>14</td>
<td>Unrealistic in TV programmes</td>
<td></td>
</tr>
<tr>
<td>Marc</td>
<td>15</td>
<td>No response</td>
<td></td>
</tr>
<tr>
<td>Marian</td>
<td>15</td>
<td>On soaps and things it is completely wrong which does annoy me. As it portrays kidney failure wrong, and makes transplants look like a piece of cake when they are not.</td>
<td></td>
</tr>
<tr>
<td>Mario</td>
<td>15</td>
<td>TV often shows kidney failure as a killer &quot;if Bob can't have a transplant, he'll die&quot; mostly American but still annoying</td>
<td></td>
</tr>
<tr>
<td>Matt</td>
<td>16</td>
<td>I have to be honest, I can't think of any situation where I've seen anything</td>
<td></td>
</tr>
<tr>
<td>Millie</td>
<td>16</td>
<td>Fictional programmes make it look so easy. Newspapers are OK if it is a true story with real people's experiences.</td>
<td></td>
</tr>
<tr>
<td>Oliver</td>
<td>16</td>
<td>No response</td>
<td></td>
</tr>
<tr>
<td>Petra</td>
<td>17</td>
<td>People don't understand them, because they are not all kidney patients. I think people should be interviewed and allowed to say about themselves, but renal patients are not the same</td>
<td></td>
</tr>
<tr>
<td>Raj</td>
<td>17</td>
<td>In Coronation Street that kid had failed kidneys and was transplanted and fine within a week. Not a true depiction. Some documentaries are energising, but TV is very compressed due to lack of time</td>
<td></td>
</tr>
<tr>
<td>Samuel</td>
<td>17</td>
<td>There is very little if any media coverage of kidney disease. What little there is portrays it as a death sentence.</td>
<td></td>
</tr>
<tr>
<td>Sara</td>
<td>18</td>
<td>No response</td>
<td></td>
</tr>
<tr>
<td>Satish</td>
<td>18</td>
<td>I have had renal failure since birth. Since growing up with this, still today there is a lack of knowledge and understanding, even with the fact that more people have diabetes + hypertension complications, so kidney disease is rarely in the media.</td>
<td></td>
</tr>
<tr>
<td>Tanya</td>
<td>19</td>
<td>No response</td>
<td></td>
</tr>
<tr>
<td>Tristram</td>
<td>19</td>
<td>It is portrayed in a bad light. For example East Enders made renal failure a simple process, all done and dusted within a month - how stupid</td>
<td></td>
</tr>
<tr>
<td>Wayne</td>
<td>22</td>
<td>Newspapers and TV programmes put the message across very well about what it can be like with kidney diseases, although there doesn't seem to be as much written about or shown on TV as I think should be</td>
<td></td>
</tr>
</tbody>
</table>

(Survey Q11a)
Table 10 Friends' understanding about living with ERF, all responses

<table>
<thead>
<tr>
<th>How much friends really understand about living with kidney failure or a transplant</th>
<th>Responses</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Friends know/understand enough/a lot</td>
<td>47</td>
<td>17.2</td>
</tr>
<tr>
<td>Close friends know/understand most (incl. only close friends understand)</td>
<td>24</td>
<td>8.8</td>
</tr>
<tr>
<td>Family understand more (incl. only family understand)</td>
<td>14</td>
<td>5.1</td>
</tr>
<tr>
<td>Total: know and understand 'enough'</td>
<td>85</td>
<td>31.1%</td>
</tr>
<tr>
<td>Friends underestimate impact, but have some knowledge/understanding of facts</td>
<td>42</td>
<td>15.4%</td>
</tr>
<tr>
<td>Friends have little or no understanding</td>
<td>118</td>
<td>43.2</td>
</tr>
<tr>
<td>Friends don't know how to react, don't want to know</td>
<td>6</td>
<td>2.2</td>
</tr>
<tr>
<td>Friends have some (limited) knowledge, understanding not referred to.</td>
<td>25</td>
<td>9.2</td>
</tr>
<tr>
<td>Friends are supportive, with some (limited) understanding</td>
<td>19</td>
<td>7.0</td>
</tr>
<tr>
<td>Friends see transplant as a permanent cure, no more problems</td>
<td>7</td>
<td>2.6</td>
</tr>
<tr>
<td>Total: know and understand little</td>
<td>168</td>
<td>64.1%</td>
</tr>
<tr>
<td>I don't tell them much</td>
<td>22</td>
<td>8.1</td>
</tr>
<tr>
<td>I don't tell people/I don't talk about it</td>
<td>12</td>
<td>4.4</td>
</tr>
<tr>
<td>I don't know what they understand</td>
<td>6</td>
<td>2.2</td>
</tr>
<tr>
<td>Total: don't ask and don't tell</td>
<td>40</td>
<td>14.7%</td>
</tr>
<tr>
<td>Friends disappeared</td>
<td>3</td>
<td>1.1</td>
</tr>
<tr>
<td>Other including gendered responses</td>
<td>9</td>
<td>3.3</td>
</tr>
</tbody>
</table>

(Survey Q11b)
<table>
<thead>
<tr>
<th>Name</th>
<th>Age RRT</th>
<th>Tell me about how much your friends really understand about living with kidney failure or a transplant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sara</td>
<td>2</td>
<td>No response</td>
</tr>
<tr>
<td>Satish</td>
<td>2</td>
<td>Many of my friends are studying medicine, so they should know what (it) means, ultimately it depends on how they view/see renal medicine. A few friends have known me since pre-16 - so they know well.</td>
</tr>
<tr>
<td>Debra</td>
<td>4</td>
<td>No response</td>
</tr>
<tr>
<td>Kelly</td>
<td>4</td>
<td>Not much, just know I have to go for treatment to help my kidneys work.</td>
</tr>
<tr>
<td>Ben</td>
<td>5</td>
<td>Close friends understand, a lot of casual friends and mates generally don't.</td>
</tr>
<tr>
<td>Tristram</td>
<td>5</td>
<td>They only understand due to the process of knowing me.</td>
</tr>
<tr>
<td>Luther</td>
<td>6</td>
<td>They don't understand or don't want to.</td>
</tr>
<tr>
<td>Amy</td>
<td>7</td>
<td>They don't know much although they are aware that sometimes I struggle with activities etc.</td>
</tr>
<tr>
<td>Edward</td>
<td>7</td>
<td>A lot.</td>
</tr>
<tr>
<td>Kieren</td>
<td>7</td>
<td>They have stood by me, but don't have a full understanding of information and effects</td>
</tr>
<tr>
<td>Oliver</td>
<td>7</td>
<td>What friends?</td>
</tr>
<tr>
<td>Cecile</td>
<td>8</td>
<td>Only my close friends who I have known for many years really understand.</td>
</tr>
<tr>
<td>Jon</td>
<td>8</td>
<td>They understand to an extent that they say I have done really well in work etc With regard to relationships, I don't think this is the case. Also my best mate has said he doesn't know how I get on with life or what I go through</td>
</tr>
<tr>
<td>Alice</td>
<td>9</td>
<td>They don't really understand. I tell them I can't drink a lot, I can't go to the toilet, I can't stay over at their house because I have dialysis. They seem to forget. They do however have a simple understanding.</td>
</tr>
<tr>
<td>Eugene</td>
<td>9</td>
<td>They understand a lot and always wish me luck before an appointment + ask me how I got on afterwards</td>
</tr>
<tr>
<td>Lucy</td>
<td>9</td>
<td>I don't think a lot of people really understand. I was so young when I had my transplant and I've been so lucky and doing so well, I don't think people understand my fears for the future</td>
</tr>
<tr>
<td>Lyn</td>
<td>9</td>
<td>They understand that my kidneys don't work and I'm on dialysis, which is basically a machine with lots of tubes coming out of it and I'm on it all night</td>
</tr>
<tr>
<td>Petra</td>
<td>9</td>
<td>They just know I have had a kidney transplant</td>
</tr>
<tr>
<td>Daniel</td>
<td>10</td>
<td>25% if you're lucky.</td>
</tr>
<tr>
<td>Jude</td>
<td>10</td>
<td>Not a lot, but that's a good thing because they treat me the same!</td>
</tr>
<tr>
<td>Marc</td>
<td>10</td>
<td>Very little. I do not talk about it and have always made a point just to get on with it. My family are obviously well aware of dialysis and all it entails, but my transplantation years have really been seen as a cure I think.</td>
</tr>
<tr>
<td>Tanya</td>
<td>11</td>
<td>Nothing, don't really discuss with them.</td>
</tr>
<tr>
<td>Anna</td>
<td>12</td>
<td>Some understand more than others - I tell some friends more than I tell others. Most of them fully understand and offer their full support whereas a handful of them just don't know how to react to things I tell them - but that's just how some people cope.</td>
</tr>
<tr>
<td>Name</td>
<td>Age RRT</td>
<td>Tell me about how much your friends really understand about living with kidney failure or a transplant</td>
</tr>
<tr>
<td>---------</td>
<td>---------</td>
<td>-----------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>James</td>
<td>12</td>
<td>They don't.</td>
</tr>
<tr>
<td>Jerry</td>
<td>12</td>
<td>No response</td>
</tr>
<tr>
<td>Matt</td>
<td>14</td>
<td>They understand very little, you try to tell them, but always stop short of the worst parts.</td>
</tr>
<tr>
<td>Carmen</td>
<td>15</td>
<td>No one really understands the fear you have of not knowing how you are going to feel the next day.</td>
</tr>
<tr>
<td>Mario</td>
<td>15</td>
<td>I have two friends that know it all but only one understands exactly. My fiancée knows and understands. My mum did my dialysis for a while (RFH had a no under 18 policy) so it is a great help.</td>
</tr>
<tr>
<td>Wayne</td>
<td>15</td>
<td>Friends don't understand at all about living with kidney failure, perhaps being a male and having male friends which are a lot less understanding than females.</td>
</tr>
<tr>
<td>Marian</td>
<td>16</td>
<td>My really close friends understand but do ask questions if they want to know something. The new friends don't know a lot, but they do ask questions as I don't mind talking about it.</td>
</tr>
<tr>
<td>Millie</td>
<td>16</td>
<td>People do understand, but pity rather than try to cope with you.</td>
</tr>
<tr>
<td>Raj</td>
<td>16</td>
<td>They can easily forget my struggle - which is good and bad.</td>
</tr>
<tr>
<td>Ajay</td>
<td>17</td>
<td>I don't think they know that much. I've never said much about it. They know about regular hospital/clinic appointments + medication</td>
</tr>
<tr>
<td>Hanna</td>
<td>17</td>
<td>No response</td>
</tr>
<tr>
<td>Samuel</td>
<td>17</td>
<td>It is only really my girlfriend that understands the physical and emotional stress I go through.</td>
</tr>
<tr>
<td>George</td>
<td>18</td>
<td>They have seen a lot over the years, and do know its been hard, but sometimes that can only be felt by other patients</td>
</tr>
<tr>
<td>Luc</td>
<td>18</td>
<td>They can't understand, so they avoid the subject.</td>
</tr>
<tr>
<td>Henry</td>
<td>19</td>
<td>Nothing prepares people for the full impact of major illness or operations unless they personally experience it or someone very close to them does eg parent/grandparent/partner</td>
</tr>
<tr>
<td>Laura</td>
<td>19</td>
<td>Some try, some don't bother. Some think you're fine and normal, some wonder why you get down, and think you're being a hypochondriac/playing on it. Most don't realise what you go through. A lot think a transplant means you're well for good now.</td>
</tr>
<tr>
<td>Gus</td>
<td>22</td>
<td>No response</td>
</tr>
</tbody>
</table>

(Survey Q11b)
Table 12 Acquaintances’ attitudes to knowing you are living with ERF, all responses

<table>
<thead>
<tr>
<th>What do you think that acquaintances think if they know you are living with ERF</th>
<th>Number of responses N</th>
<th>% 261</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don’t understand and underrate impact through ignorance</td>
<td>40</td>
<td>15.3</td>
</tr>
<tr>
<td>Think a transplant is a cure</td>
<td>13</td>
<td>5.0</td>
</tr>
<tr>
<td>Think I’m too young to have renal failure</td>
<td>7</td>
<td>2.7</td>
</tr>
<tr>
<td><strong>Total: don’t understand</strong></td>
<td><strong>60</strong></td>
<td><strong>23.0%</strong></td>
</tr>
<tr>
<td>Glad it’s not them</td>
<td>5</td>
<td>1.9</td>
</tr>
<tr>
<td>Uncomfortable, embarrassed etc</td>
<td>7</td>
<td>2.7</td>
</tr>
<tr>
<td>Pity me/feel sorry for me</td>
<td>34</td>
<td>13.0</td>
</tr>
<tr>
<td>See me as an ill person/dying person</td>
<td>15</td>
<td>5.7</td>
</tr>
<tr>
<td>Treat me differently/as if I was a disabled person</td>
<td>13</td>
<td>5.0</td>
</tr>
<tr>
<td>Don’t want an intimate relationship with me</td>
<td>4</td>
<td>1.5</td>
</tr>
<tr>
<td><strong>Total: negative and personal</strong></td>
<td><strong>78</strong></td>
<td><strong>30.0%</strong></td>
</tr>
<tr>
<td>Surprised I look so well</td>
<td>28</td>
<td>10.7</td>
</tr>
<tr>
<td>Shocked</td>
<td>20</td>
<td>7.7</td>
</tr>
<tr>
<td>Interested and/or curious</td>
<td>25</td>
<td>9.6</td>
</tr>
<tr>
<td>Impressed with how well I cope</td>
<td>14</td>
<td>5.4</td>
</tr>
<tr>
<td>Can’t tell I’m ill, treat me as normal (implies acquaintances do not know)</td>
<td>12</td>
<td>4.3</td>
</tr>
<tr>
<td>Supportive, sympathetic, caring (when they know)</td>
<td>9</td>
<td>3.4</td>
</tr>
<tr>
<td><strong>Total: positive and personal</strong></td>
<td><strong>108</strong></td>
<td><strong>41.4%</strong></td>
</tr>
<tr>
<td>They’re indifferent, not bothered</td>
<td>20</td>
<td>7.7</td>
</tr>
<tr>
<td>I don’t tell/don’t want to tell acquaintances</td>
<td>23</td>
<td>8.8</td>
</tr>
<tr>
<td>I don’t care what they think I don’t think about it (defiant)</td>
<td>7</td>
<td>2.7</td>
</tr>
<tr>
<td>I don’t know what they think</td>
<td>25</td>
<td>9.6</td>
</tr>
<tr>
<td><strong>Total: negative, denying and defiant</strong></td>
<td><strong>75</strong></td>
<td><strong>28.7%</strong></td>
</tr>
<tr>
<td><strong>Not classifiable in above</strong></td>
<td><strong>22</strong></td>
<td><strong>8.4</strong></td>
</tr>
</tbody>
</table>

(Survey Q11c)
Table 13 Acquaintances' attitudes to knowing you live with ERF, interviewees' responses

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>What do you think casual acquaintances think if they know that you're living with dialysis or a transplant?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satish</td>
<td>2</td>
<td>They'd be shocked. Even those I work with currently do not know I'm undertaking HD 3x a week. In general the public does not know what dialysis/renal transplantation entails, and it comes down to a lack of knowledge and understanding.</td>
</tr>
<tr>
<td>Kelly</td>
<td>4</td>
<td>It's a shame. Thank God it's not me</td>
</tr>
<tr>
<td>Ben</td>
<td>5</td>
<td>Not a lot!</td>
</tr>
<tr>
<td>Tristram</td>
<td>5</td>
<td>They generally (think) that they could not cope with it themselves.</td>
</tr>
<tr>
<td>Luther</td>
<td>6</td>
<td>I think they understand some of it</td>
</tr>
<tr>
<td>Amy</td>
<td>7</td>
<td>That I am unreliable and will always be feeling off colour and that I can't do the same things.</td>
</tr>
<tr>
<td>Edward</td>
<td>7</td>
<td>Surprised</td>
</tr>
<tr>
<td>Kieren</td>
<td>7</td>
<td>Don't want to deal with dialysis, rather be with someone 'normal'; transplant is normal as can be.</td>
</tr>
<tr>
<td>Cecile</td>
<td>8</td>
<td>They don't really understand</td>
</tr>
<tr>
<td>Jon</td>
<td>8</td>
<td>Casual acquaintances ... girl friends? I think that girls, specifically at school and Uni were quite naive and didn't know what to say. Now older girls do understand, however, I feel dialysis prevents relationships</td>
</tr>
<tr>
<td>Alice</td>
<td>9</td>
<td>I have had people freak out when I was younger. Now I don't tell casual acquaintances as it's on a need to know basis. They don't need to know.</td>
</tr>
<tr>
<td>Eugene</td>
<td>9</td>
<td>Think they would be surprised that I look so well and that I've had it (transplant) for so long.</td>
</tr>
<tr>
<td>Lucy</td>
<td>9</td>
<td>Shocked, always think I seem so well</td>
</tr>
<tr>
<td>Lyn</td>
<td>9</td>
<td>I don't let them know usually</td>
</tr>
<tr>
<td>Petra</td>
<td>9</td>
<td>Feel sorry for me and I would not want them to feel sorry.</td>
</tr>
<tr>
<td>Daniel</td>
<td>10</td>
<td>Oh aren't you brave. I couldn't cope.</td>
</tr>
<tr>
<td>Marc</td>
<td>10</td>
<td>I think they quietly shake their heads and think, 'Isn't it marvellous what we can do today'.</td>
</tr>
<tr>
<td>Tanya</td>
<td>11</td>
<td>Don't ever tell them I'm a transplant patient</td>
</tr>
<tr>
<td>James</td>
<td>12</td>
<td>I don't know</td>
</tr>
<tr>
<td>Jerry</td>
<td>12</td>
<td>Intrigued about it</td>
</tr>
<tr>
<td>Matt</td>
<td>14</td>
<td>They wouldn't know, but that's sometimes a worst situation to be in from my point. I don't want them to make an opinion or feel sorry for me with my transplant, but they only see a fat hairy guy and they judge on that opinion - very stereotyped.</td>
</tr>
<tr>
<td>Carmen</td>
<td>15</td>
<td>Unless people have been with you, or know what you've been through, then they feel scared or unsure of how to approach the situation.</td>
</tr>
<tr>
<td>Name</td>
<td>Age</td>
<td>What do you think casual acquaintances think if they know that you’re living with dialysis or a transplant?</td>
</tr>
<tr>
<td>-------</td>
<td>-----</td>
<td>--------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Mario</td>
<td>15</td>
<td>They are normally impressed and think I manage well.</td>
</tr>
<tr>
<td>Wayne</td>
<td>15</td>
<td>At first I think they think it is a very serious thing and that you are a completely different person to what they are, but given time are a lot more understanding.</td>
</tr>
<tr>
<td>Marian</td>
<td>16</td>
<td>If I tell people about my transplant, they don’t know a lot, but they do think it’s amazing as normally they have never met anyone with it.</td>
</tr>
<tr>
<td>Millie</td>
<td>16</td>
<td>All different, depending on the individual. Some people are very freaked out. Others are over the top with worry and getting involved.</td>
</tr>
<tr>
<td>Raj</td>
<td>16</td>
<td>They feel pity. I feel they are cautious of catching something at first, especially cases of the opposite sex.</td>
</tr>
<tr>
<td>Ajay</td>
<td>17</td>
<td>I think they would be surprised, but it is not something I would tell a casual acquaintance.</td>
</tr>
<tr>
<td>Samuel</td>
<td>17</td>
<td>They probably know very little about the condition, hence they will not know what to think.</td>
</tr>
<tr>
<td>George</td>
<td>18</td>
<td>Only when I say due to a reason where it might come out.</td>
</tr>
<tr>
<td>Luc</td>
<td>18</td>
<td>Usually morbid fascination.</td>
</tr>
<tr>
<td>Laura</td>
<td>19</td>
<td>Most think it’s amazing, but again they think ‘cause you have a transplant, it’s a cure not a treatment.</td>
</tr>
<tr>
<td>Gus</td>
<td>22</td>
<td>They think you do your treatment each night and that is the end of it. That dialysis provides 100% of the function of working kidneys and it is nothing too great to worry about.</td>
</tr>
</tbody>
</table>

No response from: Sara, Debra, Oliver, Jude, Anna, Hanna and Henry (Survey Q11c)
Table 14 Significance of association between educational attainment, all levels, and age of onset of RRT, survey respondents

<table>
<thead>
<tr>
<th>Highest educational level reached</th>
<th>Age onset RRT in 6 groups by age in years %</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0-5</td>
</tr>
<tr>
<td>None</td>
<td>13.6</td>
</tr>
<tr>
<td>Below GCSE</td>
<td>0.0</td>
</tr>
<tr>
<td>GCSE or equiv.</td>
<td>54.5</td>
</tr>
<tr>
<td>A level or equiv.</td>
<td>4.5</td>
</tr>
<tr>
<td>First degree</td>
<td>27.3</td>
</tr>
<tr>
<td>Higher degree</td>
<td>0.0</td>
</tr>
<tr>
<td>TOTAL %</td>
<td>22</td>
</tr>
</tbody>
</table>

\[ \chi^2 = 40.75 \text{ df} = 25 \text{ p} = 0.02 \]

(Survey Q 3)

---

\(^{23}\) Number of A-C grade passes at GCSE not available. Interview data revealed that the question, 'What educational level have you reached so far?' was interpreted by some respondents as what they had studied. Applies to all data presented as 'educational level'.

---
### Table 15: Significance of association between educational attainment at GCSE level and age of beginning RRT, survey subset

<table>
<thead>
<tr>
<th>Highest educational level reached</th>
<th>Age now 23 or older &amp; stable %</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>% Early onset, under 16</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Below GCSE level</td>
<td>18.2</td>
<td>6.9</td>
<td>16</td>
</tr>
<tr>
<td>GCSE level and above</td>
<td>81.8</td>
<td>93.1</td>
<td>126</td>
</tr>
<tr>
<td>Totals</td>
<td>55</td>
<td>87</td>
<td>142</td>
</tr>
</tbody>
</table>

χ² = 4.29, df = 1, p = 0.04

(Survey Q 3)

### Table 16: Significance of association between educational attainment at GCSE and A level and age of beginning RRT, survey subset

<table>
<thead>
<tr>
<th>Highest educational level reached</th>
<th>Age now 23 or older &amp; stable %</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Early onset, under 16</td>
<td></td>
<td></td>
</tr>
<tr>
<td>GCSE or equivalent and below GCSE</td>
<td>45.5</td>
<td>31.0</td>
<td>52</td>
</tr>
<tr>
<td>A level and above A level</td>
<td>54.5</td>
<td>69.0</td>
<td>90</td>
</tr>
<tr>
<td>Totals</td>
<td>55</td>
<td>87</td>
<td>142</td>
</tr>
</tbody>
</table>

χ² = 3.02, df = 1, p = 0.08

(Survey Q 3)
<table>
<thead>
<tr>
<th>Name</th>
<th>Age onset RRT</th>
<th>Highest educational attainment</th>
<th>RRT prevented getting qualifications</th>
<th>RRT upset plans for future</th>
<th>Age at end of 2006</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sara</td>
<td>2</td>
<td>first degree</td>
<td>not at all</td>
<td>not at all</td>
<td>27</td>
</tr>
<tr>
<td>Satish</td>
<td>2</td>
<td>first degree</td>
<td>a little</td>
<td>a little</td>
<td>28</td>
</tr>
<tr>
<td>Debra</td>
<td>4</td>
<td>A level or equiv</td>
<td>a little</td>
<td>not at all</td>
<td>27</td>
</tr>
<tr>
<td>Kelly</td>
<td>4</td>
<td>GCSE</td>
<td>a lot</td>
<td>a lot</td>
<td>17</td>
</tr>
<tr>
<td>Ben</td>
<td>5</td>
<td>first degree</td>
<td>a little</td>
<td>a lot</td>
<td>29</td>
</tr>
<tr>
<td>Tristram</td>
<td>5</td>
<td>GCSE</td>
<td>a little</td>
<td>completely</td>
<td>29</td>
</tr>
<tr>
<td>Luther</td>
<td>6</td>
<td>A level or equiv</td>
<td>a lot</td>
<td>a lot</td>
<td>27</td>
</tr>
<tr>
<td>Amy</td>
<td>7</td>
<td>first degree</td>
<td>not at all</td>
<td>a little</td>
<td>24</td>
</tr>
<tr>
<td>Edward</td>
<td>7</td>
<td>higher degree</td>
<td>not at all</td>
<td>a little</td>
<td>30</td>
</tr>
<tr>
<td>Jerry</td>
<td>7</td>
<td>A level or equiv</td>
<td>not at all</td>
<td>not at all</td>
<td>25</td>
</tr>
<tr>
<td>Kieren</td>
<td>7</td>
<td>none</td>
<td>a lot</td>
<td>a lot</td>
<td>29</td>
</tr>
<tr>
<td>Oliver</td>
<td>7</td>
<td>none</td>
<td>a lot</td>
<td>completely</td>
<td>26</td>
</tr>
<tr>
<td>Cecile</td>
<td>8</td>
<td>first degree</td>
<td>not at all</td>
<td>not at all</td>
<td>26</td>
</tr>
<tr>
<td>Jon</td>
<td>8</td>
<td>higher degree</td>
<td>not at all</td>
<td>not at all</td>
<td>27</td>
</tr>
<tr>
<td>Alice</td>
<td>9</td>
<td>first degree</td>
<td>a little</td>
<td>a lot</td>
<td>24</td>
</tr>
<tr>
<td>Eugene</td>
<td>9</td>
<td>GCSE</td>
<td>not at all</td>
<td>a little</td>
<td>27</td>
</tr>
<tr>
<td>Lucy</td>
<td>9</td>
<td>GCSE</td>
<td>not at all</td>
<td>not at all</td>
<td>27</td>
</tr>
<tr>
<td>Lyn</td>
<td>9</td>
<td>A level or equiv</td>
<td>completely</td>
<td>completely</td>
<td>19</td>
</tr>
<tr>
<td>Petra</td>
<td>9</td>
<td>GCSE</td>
<td>not at all</td>
<td>not at all</td>
<td>30</td>
</tr>
<tr>
<td>Daniel</td>
<td>10</td>
<td>GCSE</td>
<td>a little</td>
<td>a lot</td>
<td>27</td>
</tr>
<tr>
<td>Jude</td>
<td>10</td>
<td>A level or equiv</td>
<td>a lot</td>
<td>a little</td>
<td>22</td>
</tr>
<tr>
<td>Marc</td>
<td>10</td>
<td>higher degree</td>
<td>not at all</td>
<td>a lot</td>
<td>30</td>
</tr>
<tr>
<td>Tanya</td>
<td>11</td>
<td>first degree</td>
<td>not at all</td>
<td>a lot</td>
<td>28</td>
</tr>
<tr>
<td>Anna</td>
<td>12</td>
<td>first degree</td>
<td>not at all</td>
<td>a little</td>
<td>28</td>
</tr>
<tr>
<td>James</td>
<td>12</td>
<td>GCSE</td>
<td>completely</td>
<td>completely</td>
<td>16</td>
</tr>
<tr>
<td>Matt</td>
<td>14</td>
<td>A level or equiv</td>
<td>a lot</td>
<td>a lot</td>
<td>24</td>
</tr>
<tr>
<td>Carmen</td>
<td>15</td>
<td>first degree</td>
<td>a little</td>
<td>completely</td>
<td>24</td>
</tr>
<tr>
<td>Mario</td>
<td>15</td>
<td>A level or equiv</td>
<td>not at all</td>
<td>a little</td>
<td>28</td>
</tr>
<tr>
<td>Wayne</td>
<td>15</td>
<td>GCSE</td>
<td>a lot</td>
<td>a lot</td>
<td>20</td>
</tr>
<tr>
<td>Marian</td>
<td>16</td>
<td>A level or equiv</td>
<td>not at all</td>
<td>a lot</td>
<td>19</td>
</tr>
<tr>
<td>Millie</td>
<td>16</td>
<td>GCSE</td>
<td>completely</td>
<td>a lot</td>
<td>26</td>
</tr>
<tr>
<td>Raj</td>
<td>16</td>
<td>A level or equiv</td>
<td>completely</td>
<td>completely</td>
<td>22</td>
</tr>
<tr>
<td>Ajay</td>
<td>17</td>
<td>first degree</td>
<td>completely</td>
<td>completely</td>
<td>28</td>
</tr>
<tr>
<td>Hanna</td>
<td>17</td>
<td>A level or equiv</td>
<td>a little</td>
<td>completely</td>
<td>18</td>
</tr>
<tr>
<td>Samuel</td>
<td>17</td>
<td>higher degree</td>
<td>a lot</td>
<td>completely</td>
<td>28</td>
</tr>
<tr>
<td>George</td>
<td>18</td>
<td>GCSE</td>
<td>a lot</td>
<td>a lot</td>
<td>29</td>
</tr>
<tr>
<td>Luc</td>
<td>18</td>
<td>A level or equiv</td>
<td>completely</td>
<td>completely</td>
<td>24</td>
</tr>
<tr>
<td>Henry</td>
<td>19</td>
<td>GCSE</td>
<td>completely</td>
<td>completely</td>
<td>30</td>
</tr>
<tr>
<td>Laura</td>
<td>19</td>
<td>GCSE</td>
<td>a lot</td>
<td>a lot</td>
<td>30</td>
</tr>
<tr>
<td>Gus</td>
<td>22</td>
<td>first degree</td>
<td>a little</td>
<td>a lot</td>
<td>25</td>
</tr>
</tbody>
</table>

(Survey Qs 3 and 9)
Table 18 Importance to everyday life of factors related to education and employment, survey respondents

<table>
<thead>
<tr>
<th>How important to you is</th>
<th>% Very or quite important</th>
<th>% Not very or not at all important</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being well enough to work</td>
<td>94.8</td>
<td>5.2</td>
<td>290</td>
<td>100</td>
</tr>
<tr>
<td>Having a paid job</td>
<td>90.3</td>
<td>9.7</td>
<td>289</td>
<td>100</td>
</tr>
<tr>
<td>Having enough money to be financially independent</td>
<td>96.2</td>
<td>3.8</td>
<td>290</td>
<td>100</td>
</tr>
<tr>
<td>Studying or training</td>
<td>74.5</td>
<td>25.5</td>
<td>290</td>
<td>100</td>
</tr>
<tr>
<td>Having a voluntary job</td>
<td>31.8</td>
<td>68.2</td>
<td>283</td>
<td>100</td>
</tr>
</tbody>
</table>

(Survey Q 7a)

Table 19 Importance to everyday life of factors related to education and employment, early and late onset survey subsets

<table>
<thead>
<tr>
<th>It is very or quite important to:</th>
<th>Age now 23 or older &amp; in stable health (N=146)</th>
<th>%</th>
<th>( \chi^2 )</th>
<th>p</th>
<th>N</th>
<th>responding</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>% Early onset (N=57)</td>
<td>%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Be well enough to work</td>
<td>94.6</td>
<td>93.2</td>
<td>93.8</td>
<td>0.13</td>
<td>0.72</td>
<td>144</td>
</tr>
<tr>
<td>Have a paid job</td>
<td>85.2</td>
<td>95.4</td>
<td>91.5</td>
<td>4.47</td>
<td>0.04</td>
<td>141</td>
</tr>
<tr>
<td>Have sufficient money to be financially independent</td>
<td>91.2</td>
<td>97.7</td>
<td>95.1</td>
<td>3.12</td>
<td>0.08</td>
<td>144</td>
</tr>
<tr>
<td>Be studying or training</td>
<td>64.3</td>
<td>72.1</td>
<td>69.0</td>
<td>0.97</td>
<td>0.33</td>
<td>142</td>
</tr>
<tr>
<td>Have a voluntary job</td>
<td>35.7</td>
<td>27.1</td>
<td>30.5</td>
<td>1.19</td>
<td>0.28</td>
<td>141</td>
</tr>
</tbody>
</table>

(Survey Q 7a)
<table>
<thead>
<tr>
<th>Name</th>
<th>Age now</th>
<th>Age of onset CKD/RRT</th>
<th>Parent/carer and circumstances of breakdown</th>
<th>Contact with absent parent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amy</td>
<td>24</td>
<td>7</td>
<td>Father – followed abuse in family when Amy was 11</td>
<td>Not known but infrequent</td>
</tr>
<tr>
<td>Alice</td>
<td>24</td>
<td>9</td>
<td>Mother – lived apart for 20 years, but will go back to home country when retired and Alice married/settled</td>
<td>Good, but father abroad</td>
</tr>
<tr>
<td>Daniel</td>
<td>27</td>
<td>10</td>
<td>Mother – split up 1997 after failed transplant when Daniel 17</td>
<td>Good</td>
</tr>
<tr>
<td>Eugene</td>
<td>27</td>
<td>Birth/9</td>
<td>Mother – father left when Eugene was 16/17</td>
<td>Yes, Ok, but not good</td>
</tr>
<tr>
<td>Henry</td>
<td>30</td>
<td>Birth/19</td>
<td>Mother – parents divorced when Henry was 8</td>
<td>Good</td>
</tr>
<tr>
<td>Lucy</td>
<td>27</td>
<td>9</td>
<td>Parents separated but share home, date of estrangement not known</td>
<td>Good</td>
</tr>
<tr>
<td>Luther</td>
<td>27</td>
<td>Birth/6</td>
<td>Mother – separated when Luther 6. Mother got a boyfriend and had new baby.</td>
<td>Father dead</td>
</tr>
<tr>
<td>Marc</td>
<td>30</td>
<td>10</td>
<td>Mother (mainly) – separated when Marc was 5 or 6. Mother had boyfriend.</td>
<td>Father now abroad, little contact</td>
</tr>
<tr>
<td>Oliver</td>
<td>26</td>
<td>7</td>
<td>Mother – parents divorced when Oliver very young (3), father violent.</td>
<td>Father dead. Little contact before that.</td>
</tr>
<tr>
<td>Sara</td>
<td>27</td>
<td>2</td>
<td>Mother – separated when children (4) young.</td>
<td>Father dead, Sara hadn't seen him for 15 years</td>
</tr>
<tr>
<td>Tristram</td>
<td>29</td>
<td>Birth/5</td>
<td>Mother – divorced when Tristram was under 5, father violent</td>
<td>Reasonable contact, not close</td>
</tr>
<tr>
<td>George</td>
<td>29</td>
<td>Birth/18</td>
<td>Mother – divorced before George became ill. Stepfather at home</td>
<td>Not known – probably no contact</td>
</tr>
</tbody>
</table>
Table 21 Significance of association between living accommodation and home ownership, survey respondents' data

<table>
<thead>
<tr>
<th>Housing tenure</th>
<th>Who do you live with?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>With parent</td>
<td>With partner</td>
</tr>
<tr>
<td>Renting home</td>
<td>23.7</td>
<td>50.7</td>
</tr>
<tr>
<td>Buying home</td>
<td>76.3</td>
<td>49.3</td>
</tr>
<tr>
<td>Total</td>
<td>152</td>
<td>69</td>
</tr>
</tbody>
</table>

\[ \chi^2 = 38.79, \text{ df } = 3, \text{ p}=0.00 \]
(Survey Q1 d, e)

Table 22 Significance of association between living with parents and housing tenure and early or late age of beginning RRT, subset survey respondents' data

<table>
<thead>
<tr>
<th>Housing tenure</th>
<th>Living with parents</th>
<th>Age now 23 or older &amp; stable</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Early onset</td>
<td>Late onset</td>
<td></td>
</tr>
<tr>
<td>Rented home</td>
<td>34.8</td>
<td>12.5</td>
<td>12</td>
<td>21.8</td>
</tr>
<tr>
<td>Bought/mortgaged home</td>
<td>65.2</td>
<td>87.5</td>
<td>43</td>
<td>78.2</td>
</tr>
<tr>
<td>Totals</td>
<td>23</td>
<td>32</td>
<td>55</td>
<td>55</td>
</tr>
</tbody>
</table>

\[ \chi^2 = 3.90, \text{ df } = 1, \text{ p}= 0.05 \]
(Survey Q1 d, e)
Table 23 Occupations of interviewees and parents by age RRT, compiled from interview data

<table>
<thead>
<tr>
<th>Name</th>
<th>Age CKD/RRT</th>
<th>Education</th>
<th>Employed at time interview</th>
<th>Fathers' occupations</th>
<th>Mothers' occupations</th>
<th>Parents' Accom.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sara</td>
<td>Birth/2</td>
<td>Degree</td>
<td>No</td>
<td>Father absent</td>
<td>Admin. work</td>
<td>Rented</td>
</tr>
<tr>
<td>*Satish</td>
<td>Birth/2</td>
<td>Degree</td>
<td>P/T family</td>
<td>Self-employed in family business</td>
<td>At home</td>
<td>OO</td>
</tr>
<tr>
<td>Debra</td>
<td>4</td>
<td>A level</td>
<td>No, student, looks after baby</td>
<td>Shift worker at airport when Debra ill. Father now at home.</td>
<td>Not working at time; works full time now</td>
<td>Rented</td>
</tr>
<tr>
<td>*Kelly</td>
<td>Birth/4</td>
<td>GCSE</td>
<td>No</td>
<td>Electrician, self-employed</td>
<td>Teaching assistant</td>
<td>NK</td>
</tr>
<tr>
<td>Ben</td>
<td>5</td>
<td>Degree</td>
<td>No</td>
<td>Not known</td>
<td>Alternative therapist (from home)</td>
<td>OO</td>
</tr>
<tr>
<td>*Tristram</td>
<td>5</td>
<td>Poor GCSE</td>
<td>No</td>
<td>Not known</td>
<td>PT work, not working now</td>
<td>Rented</td>
</tr>
<tr>
<td>*Luther</td>
<td>6</td>
<td>A level</td>
<td>No student</td>
<td>Father absent</td>
<td>Ex factory worker; P/T at special school now</td>
<td>Rented</td>
</tr>
<tr>
<td>*Amy</td>
<td>7</td>
<td>Degree</td>
<td>No student</td>
<td>Adult IT trainer re-trained when single parent</td>
<td>Now abroad, little contact</td>
<td>NK</td>
</tr>
<tr>
<td>Edward</td>
<td>7</td>
<td>Degree</td>
<td>No, pending transplant</td>
<td>Management consultant</td>
<td>Ex teacher</td>
<td>OO</td>
</tr>
<tr>
<td>Kieren</td>
<td>7</td>
<td>GCSE</td>
<td>No</td>
<td>Not known</td>
<td>Not known</td>
<td>Rented</td>
</tr>
<tr>
<td>*Oliver</td>
<td>7</td>
<td>No</td>
<td>Father absent</td>
<td>Not worked after children born</td>
<td>Rented</td>
<td></td>
</tr>
<tr>
<td>Cecile</td>
<td>8</td>
<td>Degree</td>
<td>No student</td>
<td>Not known</td>
<td>Not known</td>
<td>OO</td>
</tr>
<tr>
<td>Jon</td>
<td>8</td>
<td>Degree</td>
<td>Yes Access to work</td>
<td>Youth and community worker</td>
<td>Youth and community worker</td>
<td>OO</td>
</tr>
<tr>
<td>*Alice</td>
<td>9</td>
<td>Degree</td>
<td>No</td>
<td>Local government (abroad)</td>
<td>Retail manageress</td>
<td>NK</td>
</tr>
<tr>
<td>*Eugene</td>
<td>9</td>
<td>GCSE</td>
<td>Yes, PT</td>
<td>Father absent</td>
<td>Rented</td>
<td></td>
</tr>
<tr>
<td>Lucy</td>
<td>9</td>
<td>GCSE</td>
<td>Yes</td>
<td>Printer</td>
<td>Cleaner</td>
<td>Rented</td>
</tr>
<tr>
<td>Lyn</td>
<td>9</td>
<td>A level</td>
<td>No student</td>
<td>Warehouse work</td>
<td>School kitchen</td>
<td>NK</td>
</tr>
<tr>
<td>Petra</td>
<td>9</td>
<td>GCSE</td>
<td>No</td>
<td>NK (Husband is a mechanic)</td>
<td>Hairdresser</td>
<td>Rented</td>
</tr>
<tr>
<td>*Daniel</td>
<td>10</td>
<td>GCSE</td>
<td>Yes FT</td>
<td>Teacher</td>
<td>Retired college lecturer</td>
<td>OO</td>
</tr>
<tr>
<td>Name</td>
<td>Age</td>
<td>Education</td>
<td>Employed at time interview</td>
<td>Fathers' occupations</td>
<td>Mothers' occupations</td>
<td>Parents' Accom.</td>
</tr>
<tr>
<td>--------------</td>
<td>-----</td>
<td>-----------</td>
<td>----------------------------</td>
<td>----------------------------------------</td>
<td>----------------------</td>
<td>-----------------</td>
</tr>
<tr>
<td>*Jude</td>
<td>10</td>
<td>A level</td>
<td>Yes</td>
<td>Self-employed in family business</td>
<td>Self-employed in business</td>
<td>OO</td>
</tr>
<tr>
<td>*Marc</td>
<td>10</td>
<td>Degree</td>
<td>Yes FT</td>
<td>Architect</td>
<td>Legal secretary</td>
<td>OO</td>
</tr>
<tr>
<td>*Tanya</td>
<td>11</td>
<td>Degree</td>
<td>Yes FT Temp</td>
<td>Self employed entrepreneur</td>
<td>Not relevant</td>
<td>OO</td>
</tr>
<tr>
<td>*Anna (private school)</td>
<td>12</td>
<td>Degree</td>
<td>Yes FT</td>
<td>Professional job, long hours and weekends</td>
<td>Never worked after children born</td>
<td>OO</td>
</tr>
<tr>
<td>*James</td>
<td>12</td>
<td>Poor GCSE</td>
<td>No trainee</td>
<td>Van driver</td>
<td>School helper (voluntary)</td>
<td>Rented</td>
</tr>
<tr>
<td>*Jerry</td>
<td>12</td>
<td>A level</td>
<td>Yes FT</td>
<td>IT</td>
<td>NK</td>
<td></td>
</tr>
<tr>
<td>Matt</td>
<td>14</td>
<td>A level</td>
<td>Yes FT</td>
<td></td>
<td>NK</td>
<td></td>
</tr>
<tr>
<td>*Carmen</td>
<td>15</td>
<td>Degree</td>
<td>Yes PT?</td>
<td>Part time teacher</td>
<td>OO</td>
<td></td>
</tr>
<tr>
<td>Mario</td>
<td>15</td>
<td>A level</td>
<td>No</td>
<td>Plumber/heating engineer</td>
<td>OO</td>
<td></td>
</tr>
<tr>
<td>Wayne</td>
<td>15</td>
<td>Poor GCSE</td>
<td>Yes PT</td>
<td>Fire prevention advisor - maybe self employed.</td>
<td></td>
<td>OO</td>
</tr>
</tbody>
</table>

**Over 15 years (N=11)**

| Raj          | 16  | A level   | No student                 | Not working?                          | Working              | Rented          |
| Millie       | 16  | GCSE      | Yes PT                     | Not working?                          | Public sector admin  | Rented          |
| *Marion      | 16  | A level   | Yes FT?                    | School librarian                      | OO                   |
| Ajay         | 17  | Degree    | Nursing home owner         |                                        | OO                   |
| Samuel       | 17  | Degree    | Yes PT                     | Not disclosed                         | OO                   |
| Hanna        | 17  | A level   | No, student                | Accountant                            | Not working          | OO              |
| *Luc         | 18  | A level   | Yes FT                     | Finance                               | OO                   |
| *Henry       | 18  | A level   | Yes Access                 | Musician at first then a company director | Not working at first, later a lecturer | OO              |
| *George      | 18  | Poor GCSE | No                         | Father absent (step father at home)   | Civil servant        | Rented          |
| Laura        | 18  | A level   | Yes FT                     |                                        | OO                   |
| Gus          | 19  | Degree    | No student                 | Accountant                            | OO                   |

**Key:**
- * parent interviewed in home
- OO owner occupied
- NK not known
Table 24 Upsetting of future plans and worries about the future, survey respondents' data

<table>
<thead>
<tr>
<th>How far has having renal failure?</th>
<th>Completely or a lot %</th>
<th>Not at all or a little %</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Upset your plans for the future</td>
<td>54.0</td>
<td>46.0</td>
<td>289</td>
</tr>
<tr>
<td>Made you worry about the future</td>
<td>50.9</td>
<td>49.1</td>
<td>212</td>
</tr>
</tbody>
</table>

Table 25 Upsetting of future plans by age group RRT, interviewees' survey data

<table>
<thead>
<tr>
<th>Age began RRT in years</th>
<th>How far has ERF upset your plans for the future?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Completely or a lot</td>
</tr>
<tr>
<td></td>
<td>N</td>
</tr>
<tr>
<td>0-10</td>
<td>10</td>
</tr>
<tr>
<td>11 and older</td>
<td>16</td>
</tr>
<tr>
<td>Total N</td>
<td>26</td>
</tr>
</tbody>
</table>

Table 26 Worries about the future by age RRT, interviewees' survey data

<table>
<thead>
<tr>
<th>Age began RRT in years</th>
<th>Made you worry about the future</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Completely or a lot</td>
</tr>
<tr>
<td></td>
<td>N</td>
</tr>
<tr>
<td>0-10</td>
<td>4</td>
</tr>
<tr>
<td>11 and older</td>
<td>6</td>
</tr>
<tr>
<td>Total N</td>
<td>10</td>
</tr>
</tbody>
</table>

24 Question added to survey Q9 after pilot stage of survey
25 Numbers small, percentages not presented
Table 27 Importance of having control over own health, survey respondents' data

<table>
<thead>
<tr>
<th>How important to you is?</th>
<th>Very important %</th>
<th>Quite, not very or not important %</th>
<th>N</th>
<th>Row %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling some personal control of your health</td>
<td>66.2</td>
<td>33.8</td>
<td>293</td>
<td>100</td>
</tr>
<tr>
<td>(autonomy)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being an expert patient (empowerment)</td>
<td>45.1</td>
<td>54.9</td>
<td>286</td>
<td>100</td>
</tr>
<tr>
<td>Checking your own blood results (empowerment)</td>
<td>43.0</td>
<td>57.0</td>
<td>286</td>
<td>100</td>
</tr>
</tbody>
</table>

(Survey Q6)

Table 28 Importance of health related behaviour, interviewees' survey data

<table>
<thead>
<tr>
<th>How important to you is?</th>
<th>Very N</th>
<th>Quite N</th>
<th>Not very N</th>
<th>Not at all N</th>
<th>Total N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Looking good</td>
<td>13</td>
<td>23</td>
<td>4</td>
<td>0</td>
<td>40</td>
</tr>
<tr>
<td>Feeling good about your appearance</td>
<td>18</td>
<td>19</td>
<td>3</td>
<td>0</td>
<td>40</td>
</tr>
<tr>
<td>Eating healthily</td>
<td>17</td>
<td>18</td>
<td>5</td>
<td>0</td>
<td>40</td>
</tr>
<tr>
<td>Being as fit as you can be</td>
<td>15</td>
<td>20</td>
<td>5</td>
<td>0</td>
<td>40</td>
</tr>
<tr>
<td>Taking your medication</td>
<td>34</td>
<td>6</td>
<td>0</td>
<td>0</td>
<td>40</td>
</tr>
<tr>
<td>Attending clinic regularly</td>
<td>27</td>
<td>11</td>
<td>1</td>
<td>0</td>
<td>39</td>
</tr>
<tr>
<td>Checking your own blood results</td>
<td>17</td>
<td>12</td>
<td>6</td>
<td>3</td>
<td>40</td>
</tr>
<tr>
<td>Being an expert or knowledgeable patient</td>
<td>22</td>
<td>10</td>
<td>8</td>
<td>0</td>
<td>40</td>
</tr>
<tr>
<td>Feeling some personal control of your health</td>
<td>29</td>
<td>10</td>
<td>1</td>
<td>0</td>
<td>40</td>
</tr>
<tr>
<td>Complying with advice about your treatment</td>
<td>23</td>
<td>15</td>
<td>2</td>
<td>0</td>
<td>40</td>
</tr>
</tbody>
</table>

(Survey Q6)
Table 29 Sources of support for interviewees and survey respondents

<table>
<thead>
<tr>
<th>Where do you get personal help and support?</th>
<th>Interviewees ticking box (N=40)</th>
<th>Interviewees ticking box %</th>
<th>Survey respondents ticking box (N=294)</th>
<th>Survey respondents ticking box %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family</td>
<td>34</td>
<td>85.0</td>
<td>268</td>
<td>91.2</td>
</tr>
<tr>
<td>Friends</td>
<td>29</td>
<td>72.5</td>
<td>199</td>
<td>67.7</td>
</tr>
<tr>
<td>Partner</td>
<td>15</td>
<td>37.5</td>
<td>95</td>
<td>32.3</td>
</tr>
<tr>
<td>Kidney Patients' Association (KPA)</td>
<td>3</td>
<td>7.5</td>
<td>30</td>
<td>10.2</td>
</tr>
<tr>
<td>Internet</td>
<td>7</td>
<td>17.5</td>
<td>50</td>
<td>17.0</td>
</tr>
<tr>
<td>Medical staff</td>
<td>16</td>
<td>40.0</td>
<td>159</td>
<td>54.4</td>
</tr>
<tr>
<td>Psychologist/counsellor</td>
<td>5</td>
<td>12.5</td>
<td>18</td>
<td>6.1</td>
</tr>
<tr>
<td>Social worker</td>
<td>1</td>
<td>2.5</td>
<td>21</td>
<td>7.1</td>
</tr>
<tr>
<td>Other, includes teacher, church</td>
<td>8</td>
<td>20</td>
<td>33</td>
<td>11.2</td>
</tr>
<tr>
<td>No one</td>
<td>3</td>
<td>7.5</td>
<td>8</td>
<td>2.7</td>
</tr>
</tbody>
</table>

(Survey Q 5h)
Table 30 Physical and mental health in past month, interviewees' survey data

<table>
<thead>
<tr>
<th>Over the last month have you?</th>
<th>All the time N</th>
<th>Most of the time N</th>
<th>Some of the time N</th>
<th>A little of the time N</th>
<th>None of the time N</th>
<th>Total N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive feelings</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Been feeling well</td>
<td>3</td>
<td>18</td>
<td>10</td>
<td>4</td>
<td>2</td>
<td>37</td>
</tr>
<tr>
<td>Been feeling full of energy</td>
<td>3</td>
<td>8</td>
<td>16</td>
<td>7</td>
<td>3</td>
<td>37</td>
</tr>
<tr>
<td>Been feeling happy and peaceful</td>
<td>1</td>
<td>14</td>
<td>11</td>
<td>6</td>
<td>5</td>
<td>37</td>
</tr>
<tr>
<td>Felt like seeing your friends</td>
<td>7</td>
<td>10</td>
<td>12</td>
<td>6</td>
<td>1</td>
<td>36</td>
</tr>
<tr>
<td>Negative feelings</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Been having pain</td>
<td>0</td>
<td>2</td>
<td>8</td>
<td>13</td>
<td>14</td>
<td>37</td>
</tr>
<tr>
<td>Been feeling tired</td>
<td>4</td>
<td>10</td>
<td>10</td>
<td>11</td>
<td>2</td>
<td>37</td>
</tr>
<tr>
<td>Been feeling worried or anxious</td>
<td>4</td>
<td>7</td>
<td>13</td>
<td>8</td>
<td>5</td>
<td>37</td>
</tr>
<tr>
<td>Been feeling down hearted or depressed</td>
<td>3</td>
<td>7</td>
<td>7</td>
<td>13</td>
<td>7</td>
<td>37</td>
</tr>
<tr>
<td>Been feeling lonely or isolated</td>
<td>3</td>
<td>5</td>
<td>9</td>
<td>5</td>
<td>15</td>
<td>37</td>
</tr>
<tr>
<td>Been feeling pressure to be cheerful</td>
<td>2</td>
<td>3</td>
<td>7</td>
<td>8</td>
<td>17</td>
<td>37</td>
</tr>
<tr>
<td>Seeking support</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Been talking to friends about how you feel</td>
<td>1</td>
<td>6</td>
<td>10</td>
<td>10</td>
<td>9</td>
<td>36</td>
</tr>
<tr>
<td>Been talking to family about how you feel</td>
<td>2</td>
<td>7</td>
<td>13</td>
<td>9</td>
<td>6</td>
<td>37</td>
</tr>
</tbody>
</table>

(Survey Q10)
Table 31 Significance of association between employment status by current modality, survey respondents' data

<table>
<thead>
<tr>
<th>Employment status</th>
<th>Current modality</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>% Transplanted</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>now</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working full-time</td>
<td>46.7</td>
<td>116</td>
<td>40.7</td>
</tr>
<tr>
<td>Working part-time</td>
<td>13.8</td>
<td>39</td>
<td>13.7</td>
</tr>
<tr>
<td>Doing voluntary work</td>
<td>2.9</td>
<td>9</td>
<td>3.2</td>
</tr>
<tr>
<td>Doing other paid work</td>
<td>1.0</td>
<td>3</td>
<td>1.1</td>
</tr>
<tr>
<td>Student</td>
<td>16.2</td>
<td>38</td>
<td>13.3</td>
</tr>
<tr>
<td>Not well enough to work</td>
<td>11.4</td>
<td>54</td>
<td>18.9</td>
</tr>
<tr>
<td>Can't find work</td>
<td>8.1</td>
<td>26</td>
<td>9.1</td>
</tr>
<tr>
<td>Total %</td>
<td>210</td>
<td>285</td>
<td>100</td>
</tr>
<tr>
<td></td>
<td>100</td>
<td>100</td>
<td>100</td>
</tr>
</tbody>
</table>

(\(\chi^2 = 36.91\) df = 6 p = 0.00, 3 cells less than 5)

(Survey Q5)
Table 32 Education, employment, disability status and occupation, by chronological age, compiled from interviewees' survey data and interview data

<table>
<thead>
<tr>
<th>Name</th>
<th>Age 2006</th>
<th>Age RRT</th>
<th>RRT now</th>
<th>See self as disabled</th>
<th>Education</th>
<th>Working</th>
<th>Occupation</th>
</tr>
</thead>
<tbody>
<tr>
<td>James</td>
<td>16</td>
<td>12</td>
<td>Tx</td>
<td>some</td>
<td>GCSE or equiv</td>
<td>Student, Work PT</td>
<td>Part-time at football club</td>
</tr>
<tr>
<td>Kelly</td>
<td>17</td>
<td>4</td>
<td>HD</td>
<td>yes</td>
<td>GCSE or equiv</td>
<td>Can't find work</td>
<td>Unemployed, seeking work</td>
</tr>
<tr>
<td>Hanna</td>
<td>18</td>
<td>17</td>
<td>HD</td>
<td>no</td>
<td>A level or equiv</td>
<td>Work PT</td>
<td>PT accounting work in father's office</td>
</tr>
<tr>
<td>Lyn</td>
<td>19</td>
<td>9</td>
<td>CPD</td>
<td>some</td>
<td>A level or equiv</td>
<td>Not well</td>
<td>None</td>
</tr>
<tr>
<td>Marian</td>
<td>19</td>
<td>16</td>
<td>Tx</td>
<td>some</td>
<td>A level or equiv</td>
<td>Student, Work PT</td>
<td>Bar work, cleaner/FT university student</td>
</tr>
<tr>
<td>Wayne</td>
<td>20</td>
<td>15</td>
<td>Tx</td>
<td>yes</td>
<td>GCSE or equiv</td>
<td>Student, Work PT</td>
<td>Support worker for young carers</td>
</tr>
<tr>
<td>Jude</td>
<td>22</td>
<td>10</td>
<td>CPD</td>
<td>some</td>
<td>A level or equiv</td>
<td>Work PT</td>
<td>Self-employed freelance courier</td>
</tr>
<tr>
<td>Raj</td>
<td>22</td>
<td>16</td>
<td>Tx</td>
<td>some</td>
<td>A level or equiv</td>
<td>Student</td>
<td>No other</td>
</tr>
<tr>
<td>Amy</td>
<td>24</td>
<td>7</td>
<td>Tx</td>
<td>some</td>
<td>First degree</td>
<td>Student</td>
<td>Law student</td>
</tr>
<tr>
<td>Alice</td>
<td>24</td>
<td>9</td>
<td>APD</td>
<td>missing</td>
<td>First degree</td>
<td>Student</td>
<td>None</td>
</tr>
<tr>
<td>Matt</td>
<td>24</td>
<td>14</td>
<td>Tx</td>
<td>some</td>
<td>A level or equiv</td>
<td>Work FT</td>
<td>Accounts assistant</td>
</tr>
<tr>
<td>Carmen</td>
<td>24</td>
<td>15</td>
<td>Tx</td>
<td>no</td>
<td>First degree</td>
<td>Work FT</td>
<td>Learning mentor in school</td>
</tr>
<tr>
<td>Luc</td>
<td>24</td>
<td>18</td>
<td>Tx</td>
<td>some</td>
<td>A level or equiv</td>
<td>Work FT</td>
<td>Senior finance assistant</td>
</tr>
<tr>
<td>Jerry</td>
<td>25</td>
<td>12</td>
<td>Tx</td>
<td>some</td>
<td>A level or equiv</td>
<td>Work FT</td>
<td>IT support</td>
</tr>
<tr>
<td>Gus</td>
<td>25</td>
<td>22</td>
<td>APD</td>
<td>yes</td>
<td>First degree</td>
<td>Can't find work</td>
<td>Freelance IT</td>
</tr>
<tr>
<td>Oliver</td>
<td>26</td>
<td>7</td>
<td>Tx</td>
<td>missing</td>
<td>None</td>
<td>Not look.</td>
<td>Unemployed</td>
</tr>
<tr>
<td>Cecile</td>
<td>26</td>
<td>8</td>
<td>Tx</td>
<td>some</td>
<td>First degree</td>
<td>Student, Work PT</td>
<td>Sunday in department store</td>
</tr>
<tr>
<td>Millie</td>
<td>26</td>
<td>16</td>
<td>Tx</td>
<td>no</td>
<td>GCSE or equiv</td>
<td>Work FT</td>
<td>Outpatient clerical officer</td>
</tr>
<tr>
<td>Sara</td>
<td>27</td>
<td>2</td>
<td>Tx</td>
<td>no</td>
<td>First degree</td>
<td>Work FT</td>
<td>Secretary</td>
</tr>
<tr>
<td>Debra</td>
<td>27</td>
<td>4</td>
<td>Tx</td>
<td>no</td>
<td>A level or equiv</td>
<td>Student Mother</td>
<td>Customer services (now not working)</td>
</tr>
<tr>
<td>Luther</td>
<td>27</td>
<td>6</td>
<td>HD</td>
<td>yes</td>
<td>A level or equiv</td>
<td>Not well</td>
<td>Was a chef, now not working</td>
</tr>
<tr>
<td>Jon</td>
<td>27</td>
<td>8</td>
<td>HD</td>
<td>no</td>
<td>Higher degree</td>
<td>Work FT</td>
<td>Researcher/assistant TV producer</td>
</tr>
<tr>
<td>Eugene</td>
<td>27</td>
<td>9</td>
<td>Tx</td>
<td>no</td>
<td>GCSE or equiv</td>
<td>Work PT</td>
<td>Internet supermarket shopper</td>
</tr>
<tr>
<td>Lucy</td>
<td>27</td>
<td>9</td>
<td>Tx</td>
<td>no</td>
<td>GCSE or equiv</td>
<td>Work FT</td>
<td>Private nanny</td>
</tr>
<tr>
<td>Name</td>
<td>Age 2006</td>
<td>Age RRT now</td>
<td>RRT now as disabled</td>
<td>See self as disabled</td>
<td>Education</td>
<td>Working</td>
<td>Occupation</td>
</tr>
<tr>
<td>-------</td>
<td>----------</td>
<td>-------------</td>
<td>---------------------</td>
<td>---------------------</td>
<td>-----------</td>
<td>---------</td>
<td>----------------------------------</td>
</tr>
<tr>
<td>Daniel</td>
<td>27</td>
<td>10</td>
<td>Tx</td>
<td>some</td>
<td>GCSE or equiv</td>
<td>Work FT</td>
<td>Retail project manager</td>
</tr>
<tr>
<td>Satish</td>
<td>28</td>
<td>2</td>
<td>HD</td>
<td>no</td>
<td>First degree</td>
<td>Work PT</td>
<td>Student in Pharmacy from 2004</td>
</tr>
<tr>
<td>Tanya</td>
<td>28</td>
<td>11</td>
<td>Tx</td>
<td>no</td>
<td>First degree</td>
<td>Work FT</td>
<td>Secretary</td>
</tr>
<tr>
<td>Anna</td>
<td>28</td>
<td>12</td>
<td>Tx</td>
<td>no</td>
<td>First degree</td>
<td>Work FT</td>
<td>IT consultant</td>
</tr>
<tr>
<td>Mario</td>
<td>28</td>
<td>15</td>
<td>Tx</td>
<td>no</td>
<td>A level or equiv</td>
<td>Work FT</td>
<td>IT administrator</td>
</tr>
<tr>
<td>Ajay</td>
<td>28</td>
<td>17</td>
<td>Tx</td>
<td>no</td>
<td>First degree</td>
<td>Work PT</td>
<td>Osteopath</td>
</tr>
<tr>
<td>Samuel</td>
<td>28</td>
<td>17</td>
<td>HD</td>
<td>some</td>
<td>Higher degree</td>
<td>Work FT</td>
<td>Investment manager</td>
</tr>
<tr>
<td>Ben</td>
<td>29</td>
<td>5</td>
<td>Tx</td>
<td>some</td>
<td>First degree</td>
<td>Can't find work</td>
<td>Horticulture</td>
</tr>
<tr>
<td>Tristram</td>
<td>29</td>
<td>5</td>
<td>HD</td>
<td>some</td>
<td>GCSE or equiv</td>
<td>Not well</td>
<td>Unemployed</td>
</tr>
<tr>
<td>Kieran</td>
<td>29</td>
<td>7</td>
<td>Tx</td>
<td>some</td>
<td>None</td>
<td>Student</td>
<td>Voluntary hospital radio</td>
</tr>
<tr>
<td>George</td>
<td>29</td>
<td>18</td>
<td>Tx</td>
<td>yes</td>
<td>GCSE or equiv</td>
<td>Not well</td>
<td>Unemployed</td>
</tr>
<tr>
<td>Edward</td>
<td>30</td>
<td>7</td>
<td>HD</td>
<td>no</td>
<td>Higher degree</td>
<td>Can't find work</td>
<td>Teacher(not working)</td>
</tr>
<tr>
<td>Petra</td>
<td>30</td>
<td>9</td>
<td>Tx</td>
<td>yes</td>
<td>GCSE or equiv</td>
<td>Not well</td>
<td>Was beautician, now mother at home</td>
</tr>
<tr>
<td>Marc</td>
<td>30</td>
<td>10</td>
<td>Tx</td>
<td>no</td>
<td>Higher degree</td>
<td>Work FT</td>
<td>Librarian</td>
</tr>
<tr>
<td>Henry</td>
<td>30</td>
<td>19</td>
<td>Tx</td>
<td>no</td>
<td>GCSE or equiv</td>
<td>Work PT</td>
<td>Events manager when well enough</td>
</tr>
<tr>
<td>Laura</td>
<td>30</td>
<td>19</td>
<td>Tx</td>
<td>no</td>
<td>GCSE or equiv</td>
<td>Work FT</td>
<td>Dance teacher</td>
</tr>
</tbody>
</table>

(Survey Qs 3, 4a, 4b, 5g)
Table 33 Interviewees' educational level and employment status, by name

<table>
<thead>
<tr>
<th>Education level</th>
<th>Employment status (N=40)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Full time (N=15)</td>
</tr>
<tr>
<td>Up and incl GCSE</td>
<td>Daniel, Millie</td>
</tr>
<tr>
<td>Post GCSE vocational training</td>
<td>Laura, Lucy</td>
</tr>
<tr>
<td>A level or equivalent</td>
<td>Jerry, Luc(^{27}), Mario, Matt</td>
</tr>
<tr>
<td>Degree or equivalent (15)</td>
<td>Anna, Carmen, Jon, Marc, Samuel, Sara, Tanya</td>
</tr>
</tbody>
</table>

(Survey Q3, 4 and interview data)

Table 34 Employment status of the interviewees with respect to age

<table>
<thead>
<tr>
<th>Age in years</th>
<th>N in age group</th>
<th>Employment status</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Full time (N=15)</td>
<td>Part time (N = 6) (not studying)</td>
</tr>
<tr>
<td>16-18</td>
<td>3</td>
<td>Hanna</td>
</tr>
<tr>
<td>20-24</td>
<td>10</td>
<td>Matt, Carmen, Luc</td>
</tr>
<tr>
<td>25-30</td>
<td>27</td>
<td>Jerry, Millie, Sara, Jon, Lucy, Daniel, Tanya, Anna, Mario, Samuel, Marc, Laura</td>
</tr>
</tbody>
</table>

(Survey Q1, 4 and interview data)

\(^{26}\) Said they were not well enough to work.

\(^{27}\) Studied, not passed
Table 35 Significance of association between being in paid work and early or late age of beginning RRT, survey respondents' subset data

<table>
<thead>
<tr>
<th>Employment status</th>
<th>Age now 23 or older &amp; stable</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Early onset %</td>
<td>Late onset %</td>
<td>N</td>
<td>%</td>
<td></td>
</tr>
<tr>
<td>In FT or PT paid work</td>
<td>56.6</td>
<td>75.9</td>
<td>93</td>
<td>68.4</td>
<td></td>
</tr>
<tr>
<td>Not in paid work</td>
<td>43.4</td>
<td>24.1</td>
<td>43</td>
<td>31.6</td>
<td></td>
</tr>
<tr>
<td>Totals</td>
<td>53</td>
<td>100</td>
<td>136</td>
<td>100</td>
<td>100</td>
</tr>
</tbody>
</table>

\[ \chi^2 = 5.57, \, df = 1, \, p = 0.02 \]
(Survey Q5)

Table 36 Significance of association between importance of paid work and gender, survey respondents' data

<table>
<thead>
<tr>
<th>Importance of having a paid job</th>
<th>Gender</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male %</td>
<td>Female %</td>
<td>N</td>
<td>%</td>
<td></td>
</tr>
<tr>
<td>Very or quite</td>
<td>94.0</td>
<td>86.3</td>
<td>261</td>
<td>90.3</td>
<td></td>
</tr>
<tr>
<td>Not very or not at all</td>
<td>6.0</td>
<td>13.7</td>
<td>28</td>
<td>9.7</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>150</td>
<td>139</td>
<td>289</td>
<td>289</td>
<td>100</td>
</tr>
</tbody>
</table>

\( \chi^2 = 4.849, \, df = 1 \, p = 0.03 \)
(Survey Q7)
Table 37 Importance of employment, interviewees' survey data

<table>
<thead>
<tr>
<th>How important to you is</th>
<th>Very N</th>
<th>Quite N</th>
<th>Not very N</th>
<th>Not at all N</th>
<th>Total Very or quite important N</th>
<th>Total N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being well enough to work</td>
<td>30</td>
<td>7</td>
<td>0</td>
<td>0</td>
<td>37</td>
<td>37</td>
</tr>
<tr>
<td>Having a paid job</td>
<td>27</td>
<td>7</td>
<td>2</td>
<td>0</td>
<td>34</td>
<td>36</td>
</tr>
<tr>
<td>Having a voluntary job</td>
<td>4</td>
<td>10</td>
<td>15</td>
<td>9</td>
<td>14</td>
<td>38</td>
</tr>
<tr>
<td>Studying or training</td>
<td>16</td>
<td>12</td>
<td>9</td>
<td>1</td>
<td>28</td>
<td>38</td>
</tr>
<tr>
<td>Having enough money to be financially independent</td>
<td>31</td>
<td>5</td>
<td>2</td>
<td>0</td>
<td>36</td>
<td>38</td>
</tr>
</tbody>
</table>

(Survey Q7a)

Table 38 Impact of having renal failure on finding employment, survey respondents' data

<table>
<thead>
<tr>
<th>How far has having renal failure</th>
<th>Completely or a lot %</th>
<th>A little or not at all %</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevented you from doing the job you wanted?</td>
<td>42.4</td>
<td>57.6</td>
<td>283</td>
<td>100</td>
</tr>
<tr>
<td>Made it hard to get any job?</td>
<td>37.8</td>
<td>62.2</td>
<td>278</td>
<td>100</td>
</tr>
</tbody>
</table>

(Survey Q9)

Table 39 Impact of ERF on finding employment by age RRT, interviewees' survey data

<table>
<thead>
<tr>
<th>Age RRT in years (N=39)</th>
<th>Prevented you from doing the job you wanted? (N)</th>
<th>Made it hard to get any job (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Completely or a lot</td>
<td>A little or not at all</td>
</tr>
<tr>
<td>0-10</td>
<td>7</td>
<td>14</td>
</tr>
<tr>
<td>11-20</td>
<td>8</td>
<td>11</td>
</tr>
<tr>
<td>Total N</td>
<td>15</td>
<td>24</td>
</tr>
</tbody>
</table>

(Survey Q9)
Table 40 Importance of social life, respondents' survey data

<table>
<thead>
<tr>
<th>How important to you is</th>
<th>Row % Very or quite important</th>
<th>Row % Not very or not at all important</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Having one or two close friends or family?</td>
<td>99.3</td>
<td>0.7</td>
<td>293</td>
</tr>
<tr>
<td>Having a large number of friends?</td>
<td>56.8</td>
<td>43.2</td>
<td>294</td>
</tr>
<tr>
<td>Having an intimate partner, husband or wife?</td>
<td>69.6</td>
<td>30.4</td>
<td>276</td>
</tr>
<tr>
<td>Being able to join in all activities with friends?</td>
<td>86.1</td>
<td>13.9</td>
<td>294</td>
</tr>
<tr>
<td>Meeting new people, doing new things?</td>
<td>79.0</td>
<td>21.0</td>
<td>291</td>
</tr>
<tr>
<td>Doing the same things socially each week/month?</td>
<td>66.6</td>
<td>33.4</td>
<td>290</td>
</tr>
<tr>
<td>Having religious faith?</td>
<td>37.1</td>
<td>62.9</td>
<td>286</td>
</tr>
<tr>
<td>Having a hobby or interest?</td>
<td>89.4</td>
<td>10.6</td>
<td>293</td>
</tr>
<tr>
<td>Having access to a computer and the internet?</td>
<td>74.0</td>
<td>26.0</td>
<td>292</td>
</tr>
<tr>
<td>Telling people you work/study with about your illness?</td>
<td>49.0</td>
<td>51.0</td>
<td>288</td>
</tr>
</tbody>
</table>

(Survey Q7a)
Table 41 Importance of social life, interviewees' survey data

<table>
<thead>
<tr>
<th>How important to you is</th>
<th>Very N</th>
<th>Quite N</th>
<th>Not very N</th>
<th>Not at all N</th>
<th>Total N</th>
<th>Total Very or quite important N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Having one or two close friends or family</td>
<td>36</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>38</td>
<td>38</td>
</tr>
<tr>
<td>Having a large number of friends</td>
<td>7</td>
<td>15</td>
<td>4</td>
<td>2</td>
<td>38</td>
<td>22</td>
</tr>
<tr>
<td>Having a partner/husband/wife</td>
<td>16</td>
<td>13</td>
<td>8</td>
<td>0</td>
<td>37</td>
<td>29</td>
</tr>
<tr>
<td>Being able to join in with all friends do</td>
<td>17</td>
<td>15</td>
<td>5</td>
<td>1</td>
<td>38</td>
<td>32</td>
</tr>
<tr>
<td>Meeting new people &amp; doing new things</td>
<td>13</td>
<td>15</td>
<td>9</td>
<td>1</td>
<td>38</td>
<td>28</td>
</tr>
<tr>
<td>Doing the same things socially each week</td>
<td>8</td>
<td>19</td>
<td>10</td>
<td>1</td>
<td>38</td>
<td>27</td>
</tr>
<tr>
<td>Having a religious faith</td>
<td>6</td>
<td>9</td>
<td>8</td>
<td>15</td>
<td>38</td>
<td>15</td>
</tr>
<tr>
<td>Having a hobby or interest</td>
<td>18</td>
<td>19</td>
<td>1</td>
<td>0</td>
<td>38</td>
<td>37</td>
</tr>
<tr>
<td>Having access to a computer &amp; internet</td>
<td>19</td>
<td>12</td>
<td>4</td>
<td>3</td>
<td>38</td>
<td>29</td>
</tr>
<tr>
<td>Telling people you work/study with about your illness</td>
<td>7</td>
<td>11</td>
<td>11</td>
<td>8</td>
<td>37</td>
<td>18</td>
</tr>
</tbody>
</table>

(Survey Q7a)

Table 42 Frequency of social outings, interviewees' survey data

<table>
<thead>
<tr>
<th>How often do you</th>
<th>Every day N</th>
<th>Most days N</th>
<th>Weekly N</th>
<th>Rarely N</th>
<th>Never N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Go out socially with family (N=37)</td>
<td>1</td>
<td>7</td>
<td>18</td>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td>Go out socially with friends (N=37)</td>
<td>0</td>
<td>8</td>
<td>19</td>
<td>9</td>
<td>1</td>
</tr>
<tr>
<td>Miss outings because unwell (N=37)</td>
<td>0</td>
<td>2</td>
<td>4</td>
<td>24</td>
<td>7</td>
</tr>
</tbody>
</table>

(Survey Q7b)
Table 43 Interviewees who consider friends and social life important by gender, survey data

<table>
<thead>
<tr>
<th>How important is?</th>
<th>Very or quite important</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N Male</td>
<td>% Male</td>
<td>N Female</td>
<td>% Female</td>
<td>N Total</td>
</tr>
<tr>
<td>N answering question</td>
<td>24</td>
<td>100</td>
<td>16</td>
<td>100</td>
<td>40</td>
</tr>
<tr>
<td>Having one or two close friends and family</td>
<td>24</td>
<td>100</td>
<td>16</td>
<td>100</td>
<td>40</td>
</tr>
<tr>
<td>Having a large number of friends</td>
<td>12</td>
<td>50.0</td>
<td>12</td>
<td>75.0</td>
<td>24</td>
</tr>
<tr>
<td>Having an intimate partner</td>
<td>19</td>
<td>79.2</td>
<td>12</td>
<td>75.0</td>
<td>31</td>
</tr>
<tr>
<td>Being able to join in with all that friends do</td>
<td>19</td>
<td>79.2</td>
<td>15</td>
<td>93.8</td>
<td>34</td>
</tr>
<tr>
<td>Meeting new people, doing new things</td>
<td>16</td>
<td>66.7</td>
<td>14</td>
<td>87.5</td>
<td>30</td>
</tr>
<tr>
<td>Doing same things socially every week or month</td>
<td>15</td>
<td>62.5</td>
<td>14</td>
<td>87.5</td>
<td>29</td>
</tr>
</tbody>
</table>

(Survey Q7a)
Table 44 Challenges of having renal failure, interviewees’ survey data

<table>
<thead>
<tr>
<th>How far has having renal failure:</th>
<th>Completely</th>
<th>A lot</th>
<th>A little</th>
<th>Not at all</th>
<th>Total</th>
<th>Completely or a lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevented you from getting the qualifications you wanted</td>
<td>7</td>
<td>9</td>
<td>8</td>
<td>14</td>
<td>38</td>
<td>16</td>
</tr>
<tr>
<td>Prevented you from getting the job you wanted</td>
<td>8</td>
<td>7</td>
<td>9</td>
<td>13</td>
<td>37</td>
<td>15</td>
</tr>
<tr>
<td>Made it hard to get any job</td>
<td>5</td>
<td>9</td>
<td>11</td>
<td>13</td>
<td>38</td>
<td>14</td>
</tr>
<tr>
<td>Made it more difficult to make close friends</td>
<td>3</td>
<td>6</td>
<td>8</td>
<td>21</td>
<td>38</td>
<td>9</td>
</tr>
<tr>
<td>Made it more difficult to keep friends’</td>
<td>3</td>
<td>5</td>
<td>4</td>
<td>26</td>
<td>38</td>
<td>8</td>
</tr>
<tr>
<td>Made you feel short of time for other things</td>
<td>8</td>
<td>8</td>
<td>8</td>
<td>13</td>
<td>37</td>
<td>16</td>
</tr>
<tr>
<td>Made it difficult to talk about yourself</td>
<td>5</td>
<td>11</td>
<td>10</td>
<td>12</td>
<td>38</td>
<td>16</td>
</tr>
<tr>
<td>Made you feel abnormal or different from other people</td>
<td>9</td>
<td>3</td>
<td>17</td>
<td>9</td>
<td>38</td>
<td>12</td>
</tr>
<tr>
<td>Made you upset about the scars on your body</td>
<td>4</td>
<td>7</td>
<td>7</td>
<td>7</td>
<td>25</td>
<td>11</td>
</tr>
<tr>
<td>Upset your plans for the future</td>
<td>11</td>
<td>13</td>
<td>7</td>
<td>38</td>
<td>7</td>
<td>24</td>
</tr>
<tr>
<td>Made you worry about the future</td>
<td>8</td>
<td>2</td>
<td>10</td>
<td>3</td>
<td>23</td>
<td>10</td>
</tr>
<tr>
<td>Made you more dependent on friend &amp; family than you like</td>
<td>7</td>
<td>11</td>
<td>10</td>
<td>10</td>
<td>38</td>
<td>18</td>
</tr>
<tr>
<td>Made you more dependent on strangers than you like</td>
<td>4</td>
<td>2</td>
<td>10</td>
<td>22</td>
<td>38</td>
<td>6</td>
</tr>
</tbody>
</table>

(Survey Q9)
Table 45 Challenges of renal failure, survey respondents

<table>
<thead>
<tr>
<th>How far has having renal failure</th>
<th>Row% Completely or a lot</th>
<th>Row % Not at all or a little</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Made it more difficult to make close friends?</td>
<td>25.2</td>
<td>74.8</td>
<td>286</td>
</tr>
<tr>
<td>Made it more difficult to keep friends?</td>
<td>24.2</td>
<td>75.8</td>
<td>285</td>
</tr>
<tr>
<td>Made you feel very short of time for anything else?</td>
<td>38.4</td>
<td>61.6</td>
<td>281</td>
</tr>
<tr>
<td>Made it difficult to talk about yourself?</td>
<td>31.8</td>
<td>68.2</td>
<td>286</td>
</tr>
<tr>
<td>Upset your plans for the future?</td>
<td>54.0</td>
<td>46.0</td>
<td>289</td>
</tr>
<tr>
<td>Made you worry about the future?</td>
<td>50.9</td>
<td>49.1</td>
<td>212</td>
</tr>
<tr>
<td>Made you more dependent on friends and family than you like?</td>
<td>43.4</td>
<td>56.6</td>
<td>286</td>
</tr>
<tr>
<td>Made you more dependent on strangers than you like?</td>
<td>21.1</td>
<td>78.9</td>
<td>285</td>
</tr>
</tbody>
</table>

(Survey Q9)
<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>RRT</th>
<th>Difficult to make close friends</th>
<th>Difficult to keep friends</th>
<th>Hard to talk about self</th>
<th>Feel abnormal or different</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sara</td>
<td>2</td>
<td>a little</td>
<td>not at all</td>
<td>Completely or a lot</td>
<td>Completely or a lot</td>
<td></td>
</tr>
<tr>
<td>Satish</td>
<td>2</td>
<td>not at all</td>
<td>not at all</td>
<td>A little or not at all</td>
<td>A little or not at all</td>
<td></td>
</tr>
<tr>
<td>Debra</td>
<td>4</td>
<td>not at all</td>
<td>not at all</td>
<td>A little or not at all</td>
<td>A little or not at all</td>
<td></td>
</tr>
<tr>
<td>Kelly</td>
<td>4</td>
<td>a little</td>
<td>a lot</td>
<td>Completely or a lot</td>
<td>A little or not at all</td>
<td></td>
</tr>
<tr>
<td>Ben</td>
<td>5</td>
<td>a lot</td>
<td>a lot</td>
<td>A little or not at all</td>
<td>A little or not at all</td>
<td></td>
</tr>
<tr>
<td>Tristram</td>
<td>5</td>
<td>a little</td>
<td>not at all</td>
<td>Completely or a lot</td>
<td>Completely or a lot</td>
<td></td>
</tr>
<tr>
<td>Luther</td>
<td>6</td>
<td>a lot</td>
<td>a lot</td>
<td>Completely or a lot</td>
<td>Completely or a lot</td>
<td></td>
</tr>
<tr>
<td>Amy</td>
<td>7</td>
<td>a little</td>
<td>not at all</td>
<td>A little or not at all</td>
<td>A little or not at all</td>
<td></td>
</tr>
<tr>
<td>Edward</td>
<td>7</td>
<td>not at all</td>
<td>not at all</td>
<td>A little or not at all</td>
<td>A little or not at all</td>
<td></td>
</tr>
<tr>
<td>Kieren</td>
<td>7</td>
<td>a lot</td>
<td>a little</td>
<td>Completely or a lot</td>
<td>Completely or a lot</td>
<td></td>
</tr>
<tr>
<td>Oliver</td>
<td>7</td>
<td>completely</td>
<td>completely</td>
<td>Completely or a lot</td>
<td>Completely or a lot</td>
<td></td>
</tr>
<tr>
<td>Cecile</td>
<td>8</td>
<td>not at all</td>
<td>not at all</td>
<td>A little or not at all</td>
<td>A little or not at all</td>
<td></td>
</tr>
<tr>
<td>Jon</td>
<td>8</td>
<td>not at all</td>
<td>not at all</td>
<td>A little or not at all</td>
<td>A little or not at all</td>
<td></td>
</tr>
<tr>
<td>Alice</td>
<td>9</td>
<td>a little</td>
<td>not at all</td>
<td>A little or not at all</td>
<td>A little or not at all</td>
<td></td>
</tr>
<tr>
<td>Eugene</td>
<td>9</td>
<td>not at all</td>
<td>not at all</td>
<td>A little or not at all</td>
<td>A little or not at all</td>
<td></td>
</tr>
<tr>
<td>Lucy</td>
<td>9</td>
<td>not at all</td>
<td>not at all</td>
<td>A little or not at all</td>
<td>A little or not at all</td>
<td></td>
</tr>
<tr>
<td>Lyn</td>
<td>9</td>
<td>completely</td>
<td>completely</td>
<td>Completely or a lot</td>
<td>Completely or a lot</td>
<td></td>
</tr>
<tr>
<td>Petra</td>
<td>9</td>
<td>not at all</td>
<td>not at all</td>
<td>A little or not at all</td>
<td>A little or not at all</td>
<td></td>
</tr>
<tr>
<td>Daniel</td>
<td>10</td>
<td>not at all</td>
<td>not at all</td>
<td>A little or not at all</td>
<td>A little or not at all</td>
<td></td>
</tr>
<tr>
<td>Jude</td>
<td>10</td>
<td>not at all</td>
<td>a little</td>
<td>A little or not at all</td>
<td>A little or not at all</td>
<td></td>
</tr>
<tr>
<td>Marc</td>
<td>10</td>
<td>not at all</td>
<td>not at all</td>
<td>A little or not at all</td>
<td>A little or not at all</td>
<td></td>
</tr>
<tr>
<td>Tanya</td>
<td>11</td>
<td>a lot</td>
<td>not at all</td>
<td>Completely or a lot</td>
<td>Completely or a lot</td>
<td></td>
</tr>
<tr>
<td>Anna</td>
<td>12</td>
<td>not at all</td>
<td>not at all</td>
<td>A little or not at all</td>
<td>A little or not at all</td>
<td></td>
</tr>
<tr>
<td>James</td>
<td>12</td>
<td>completely</td>
<td>completely</td>
<td>Completely or a lot</td>
<td>Completely or a lot</td>
<td></td>
</tr>
<tr>
<td>Jerry</td>
<td>12</td>
<td>a little</td>
<td>a little</td>
<td>A little or not at all</td>
<td>A little or not at all</td>
<td></td>
</tr>
<tr>
<td>Matt</td>
<td>14</td>
<td>a lot</td>
<td>a little</td>
<td>Completely or a lot</td>
<td>Completely or a lot</td>
<td></td>
</tr>
<tr>
<td>Carmen</td>
<td>15</td>
<td>not at all</td>
<td>not at all</td>
<td>Completely or a lot</td>
<td>A little or not at all</td>
<td></td>
</tr>
<tr>
<td>Mario</td>
<td>15</td>
<td>not at all</td>
<td>not at all</td>
<td>A little or not at all</td>
<td>A little or not at all</td>
<td></td>
</tr>
<tr>
<td>Wayne</td>
<td>15</td>
<td>not at all</td>
<td>not at all</td>
<td>Completely or a lot</td>
<td>Completely or a lot</td>
<td></td>
</tr>
<tr>
<td>Marian</td>
<td>16</td>
<td>not at all</td>
<td>not at all</td>
<td>A little or not at all</td>
<td>A little or not at all</td>
<td></td>
</tr>
<tr>
<td>Millie</td>
<td>16</td>
<td>not at all</td>
<td>not at all</td>
<td>A little or not at all</td>
<td>A little or not at all</td>
<td></td>
</tr>
<tr>
<td>Raj</td>
<td>16</td>
<td>not at all</td>
<td>not at all</td>
<td>A little or not at all</td>
<td>A little or not at all</td>
<td></td>
</tr>
<tr>
<td>Ajay</td>
<td>17</td>
<td>not at all</td>
<td>not at all</td>
<td>Completely or a lot</td>
<td>A little or not at all</td>
<td></td>
</tr>
<tr>
<td>Hanna</td>
<td>17</td>
<td>a little</td>
<td>not at all</td>
<td>A little or not at all</td>
<td>A little or not at all</td>
<td></td>
</tr>
<tr>
<td>Samuel</td>
<td>17</td>
<td>not at all</td>
<td>not at all</td>
<td>A little or not at all</td>
<td>A little or not at all</td>
<td></td>
</tr>
<tr>
<td>George</td>
<td>18</td>
<td>a little</td>
<td>not at all</td>
<td>A little or not at all</td>
<td>A little or not at all</td>
<td></td>
</tr>
<tr>
<td>Luc</td>
<td>18</td>
<td>a lot</td>
<td>a lot</td>
<td>Completely or a lot</td>
<td>Completely or a lot</td>
<td></td>
</tr>
<tr>
<td>Henry</td>
<td>19</td>
<td>not at all</td>
<td>a lot</td>
<td>Completely or a lot</td>
<td>Completely or a lot</td>
<td></td>
</tr>
<tr>
<td>Laura</td>
<td>19</td>
<td>not at all</td>
<td>a little</td>
<td>A little or not at all</td>
<td>A little or not at all</td>
<td></td>
</tr>
<tr>
<td>Gus</td>
<td>22</td>
<td>not at all</td>
<td>not at all</td>
<td>A little or not at all</td>
<td>Completely or a lot</td>
<td></td>
</tr>
</tbody>
</table>

(Survey Q9)
Table 47 Probability levels of associations between social relationships with friends and family and age of onset RRT, subset survey respondents' data (N=146)

<table>
<thead>
<tr>
<th>Social relationships: everyday social life</th>
<th>% &lt; 16 N=57</th>
<th>% &gt;= 16 N=89</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>How often do you go out socially with family? Category 'weekly or more often'</td>
<td>63.5</td>
<td>60.2</td>
<td>0.68</td>
</tr>
<tr>
<td>How often do you go out socially with friends? Category 'weekly or more often'</td>
<td>61.1</td>
<td>71.3</td>
<td>0.21</td>
</tr>
<tr>
<td>How important is having a large number of friends? Category 'very or quite important'</td>
<td>60.7</td>
<td>47.2</td>
<td>0.11</td>
</tr>
<tr>
<td>How important is being able to join in activities with friends? Category 'very or quite important'</td>
<td>89.3</td>
<td>84.3</td>
<td>0.39</td>
</tr>
<tr>
<td>How important is meeting new people and doing new things? Category 'very or quite important'</td>
<td>78.6</td>
<td>69.0</td>
<td>0.21</td>
</tr>
<tr>
<td>How important is doing the same things socially each week? Category 'very or quite important'</td>
<td>67.9</td>
<td>63.2</td>
<td>0.57</td>
</tr>
<tr>
<td>How important is having a hobby or interest? Category 'very or quite important'</td>
<td>94.5</td>
<td>83.1</td>
<td>0.04</td>
</tr>
</tbody>
</table>

Table 48 Probability levels of associations between challenges to normal social life and age of onset RRT, subset survey respondents' data (N=146)

<table>
<thead>
<tr>
<th>Challenges of having ERF: How far has ERF</th>
<th>% &lt; 16 N=57</th>
<th>% &gt;= 16 N=89</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Made it more difficult to make close friends?</td>
<td>30.9</td>
<td>20.2</td>
<td>0.15</td>
</tr>
<tr>
<td>Made it more difficult to keep friends?</td>
<td>22.2</td>
<td>22.6</td>
<td>0.96</td>
</tr>
<tr>
<td>Made you feel very short of time for other things?</td>
<td>35.8</td>
<td>33.3</td>
<td>0.76</td>
</tr>
<tr>
<td>Made it more difficult to talk about yourself?</td>
<td>33.3</td>
<td>28.6</td>
<td>0.55</td>
</tr>
<tr>
<td>Made you feel abnormal or different?</td>
<td>30.9</td>
<td>31.0</td>
<td>1.00</td>
</tr>
<tr>
<td>Made you feel upset about the scars on your body?</td>
<td>28.6</td>
<td>34.9</td>
<td>0.50</td>
</tr>
<tr>
<td>Made you worry about the future?</td>
<td>43.6</td>
<td>51.6</td>
<td>0.43</td>
</tr>
<tr>
<td>Upset your plans for the future?</td>
<td>44.6</td>
<td>55.3</td>
<td>0.22</td>
</tr>
<tr>
<td>Made you more dependent on friends and family than you like?</td>
<td>32.7</td>
<td>41.7</td>
<td>0.29</td>
</tr>
<tr>
<td>Made you more dependent on strangers than you like?</td>
<td>14.5</td>
<td>18.1</td>
<td>0.59</td>
</tr>
</tbody>
</table>

Compiled from 2 x 2 contingency tables (not presented) using grouped data from survey questions
7 a: categories 'very and quite important' combined, and 'not very and not at all important' combined;
7 b: categories 'every day, most days and weekly' combined, and 'rarely and never' combined.

Compiled from 2 x 2 contingency tables using grouped data from survey question 9: categories 'completely and a lot' combined and 'a little and not at all' combined.
Table 49: Significance of association between shortage of time for other things and modality, respondents' survey data

<table>
<thead>
<tr>
<th>Feel short of time for other things</th>
<th>Transplant %</th>
<th>Dialysis %</th>
<th>Total %</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completely or a lot</td>
<td>27.9</td>
<td>66.2</td>
<td>38.4</td>
<td>108</td>
</tr>
<tr>
<td>A little or not at all</td>
<td>72.1</td>
<td>33.8</td>
<td>61.6</td>
<td>173</td>
</tr>
<tr>
<td>Totals</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>281</td>
</tr>
</tbody>
</table>

χ² = 34.6, p < 0.001
(Survey Q 9)

Table 50: Frequency of going out with friends by modality, interviewees' survey data

<table>
<thead>
<tr>
<th>How often do you?</th>
<th>N answering Q7</th>
<th>% Transplant</th>
<th>N Dialysis</th>
<th>% Dialysis</th>
<th>N Total</th>
<th>% N=37</th>
</tr>
</thead>
<tbody>
<tr>
<td>Go out socially with friends weekly or more often?</td>
<td>26</td>
<td>11</td>
<td>20</td>
<td>76.9</td>
<td>7</td>
<td>63.6</td>
</tr>
<tr>
<td>Miss outings because you feel unwell weekly or more often</td>
<td>3</td>
<td>11.5</td>
<td>3</td>
<td>27.3</td>
<td>6</td>
<td>16.2</td>
</tr>
</tbody>
</table>

(Survey Q7b)

Table 51: Significance of association between frequency of going out with friends by modality, survey respondents' data

<table>
<thead>
<tr>
<th>How often do you go out socially with friends</th>
<th>Transplant %</th>
<th>Dialysis %</th>
<th>Total N</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weekly or more often</td>
<td>75.1</td>
<td>60.0</td>
<td>205</td>
<td>71.2</td>
</tr>
<tr>
<td>Rarely or never</td>
<td>24.9</td>
<td>40.0</td>
<td>83</td>
<td>28.8</td>
</tr>
<tr>
<td>Total N %</td>
<td>213</td>
<td>100</td>
<td>288</td>
<td>100</td>
</tr>
</tbody>
</table>

χ² = 6.2, p = 0.01
(Survey Q7b)

---

37 interviewees answered this question, data for category 'weekly or more often' only displayed.
Table 52 Significance of association between frequency of missing outings because you feel unwell and modality, respondents’ survey data

<table>
<thead>
<tr>
<th>How often do you miss outings</th>
<th>Transplant %</th>
<th>Dialysis %</th>
<th>Total %</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weekly or more often</td>
<td>10.3</td>
<td>39.2</td>
<td>17.7</td>
<td>51</td>
</tr>
<tr>
<td>Rarely or never</td>
<td>89.7</td>
<td>60.8</td>
<td>82.3</td>
<td>237</td>
</tr>
<tr>
<td>Totals</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>288</td>
</tr>
</tbody>
</table>

\[ \chi^2 = 31.5, p < 0.001 \]

Table 53 Significance of associations between challenges of making and keeping friends and modality, survey respondents’ data

<table>
<thead>
<tr>
<th>Has renal failure made it more difficult to make close friends?</th>
<th>Transplant %</th>
<th>Dialysis %</th>
<th>Total N</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completely or a lot</td>
<td>22.5</td>
<td>32.5</td>
<td>72</td>
<td>25.2</td>
</tr>
<tr>
<td>A little or not at all</td>
<td>77.5</td>
<td>67.5</td>
<td>214</td>
<td>74.8</td>
</tr>
<tr>
<td>Totals</td>
<td>209</td>
<td>77</td>
<td>286</td>
<td>100</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Has renal failure made it more difficult to keep friends?</th>
<th>Transplant %</th>
<th>Dialysis %</th>
<th>Total N</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completely or a lot</td>
<td>20.7</td>
<td>33.8</td>
<td>69</td>
<td>24.2</td>
</tr>
<tr>
<td>A little or not at all</td>
<td>79.3</td>
<td>66.2</td>
<td>216</td>
<td>75.8</td>
</tr>
<tr>
<td>Total</td>
<td>208</td>
<td>77</td>
<td>285</td>
<td>100</td>
</tr>
</tbody>
</table>

\[ \chi^2 = 3.0, p = 0.09 \) (making friends)
\[ \chi^2 = 5.2, p = 0.02 \) (keeping friends)

(Survey Qs 5d, 9)
Table 54 Interviewees who encountered challenges in making and keeping friends by modality, survey data

<table>
<thead>
<tr>
<th>How far has renal failure made it completely or a lot(^{31})</th>
<th>Transplant N(^{31})</th>
<th>% N=28</th>
<th>Dialysis N(^{31})</th>
<th>% N=12</th>
<th>Total N</th>
<th>% 40</th>
</tr>
</thead>
<tbody>
<tr>
<td>More difficult to make close friends?</td>
<td>7</td>
<td>25.0</td>
<td>2</td>
<td>16.7</td>
<td>9</td>
<td>23</td>
</tr>
<tr>
<td>More difficult to keep friends?</td>
<td>5</td>
<td>17.9</td>
<td>3</td>
<td>25.0</td>
<td>8</td>
<td>20</td>
</tr>
<tr>
<td>You short of time for other things?</td>
<td>10</td>
<td>35.7</td>
<td>8</td>
<td>66.7</td>
<td>18</td>
<td>45</td>
</tr>
</tbody>
</table>

(Survey Qs 5d, 9)

Table 55 Physical and mental health in past month, survey respondents' data

<table>
<thead>
<tr>
<th>Over the last month have you?</th>
<th>All or most of the time %</th>
<th>Some, a little or none of the time %</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Positive feelings</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Been feeling well</td>
<td>70.5</td>
<td>29.5</td>
<td>292</td>
</tr>
<tr>
<td>Been feeling full of energy</td>
<td>42.3</td>
<td>57.7</td>
<td>291</td>
</tr>
<tr>
<td>Been feeling happy and peaceful</td>
<td>52.2</td>
<td>47.8</td>
<td>288</td>
</tr>
<tr>
<td>Feeling like seeing your friends</td>
<td>49.7</td>
<td>50.3</td>
<td>288</td>
</tr>
<tr>
<td><strong>Negative feelings</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Been having pain</td>
<td>9.9</td>
<td>90.1</td>
<td>292</td>
</tr>
<tr>
<td>Been feeling tired or worn out</td>
<td>32.0</td>
<td>68.0</td>
<td>291</td>
</tr>
<tr>
<td>Been feeling worried or anxious</td>
<td>25.0</td>
<td>75.0</td>
<td>292</td>
</tr>
<tr>
<td>Been feeling downhearted or depressed</td>
<td>20.9</td>
<td>79.1</td>
<td>292</td>
</tr>
<tr>
<td>Been feeling lonely or isolated</td>
<td>18.6</td>
<td>81.4</td>
<td>291</td>
</tr>
<tr>
<td>Been feeling pressure to be positive</td>
<td>19.0</td>
<td>81.0</td>
<td>289</td>
</tr>
<tr>
<td><strong>Seeking support</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Been talking to friends about how you feel</td>
<td>16.8</td>
<td>83.2</td>
<td>291</td>
</tr>
<tr>
<td>Been talking to family about how you feel</td>
<td>26.0</td>
<td>74.0</td>
<td>292</td>
</tr>
</tbody>
</table>

(Survey Q10)

\(^{31}\) 40 interviewees answered this question, N for category 'completely or a lot' only displayed.
Table 56 Accommodation, housing tenure, age and education, by name, interviewees’ survey data

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Age RRT</th>
<th>Living with</th>
<th>Home ownership</th>
<th>Educational attainment&lt;sup&gt;23&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sara</td>
<td>27</td>
<td>2</td>
<td>With parent</td>
<td>rented</td>
<td>first degree or equiv</td>
</tr>
<tr>
<td>Satish</td>
<td>28</td>
<td>2</td>
<td>With parent</td>
<td>bought or on mortgage</td>
<td>first degree or equiv</td>
</tr>
<tr>
<td>Debra</td>
<td>27</td>
<td>4</td>
<td>With parent</td>
<td>bought or on mortgage</td>
<td>A level or equiv</td>
</tr>
<tr>
<td>Kelly</td>
<td>17</td>
<td>4</td>
<td>With parent</td>
<td>bought or on mortgage</td>
<td>A level or equiv</td>
</tr>
<tr>
<td>Ben</td>
<td>29</td>
<td>5</td>
<td>With parent</td>
<td>missing</td>
<td>first degree or equiv</td>
</tr>
<tr>
<td>Tristram</td>
<td>29</td>
<td>5</td>
<td>With parent</td>
<td>rented</td>
<td>GCSE</td>
</tr>
<tr>
<td>Luther</td>
<td>27</td>
<td>6</td>
<td>With parent</td>
<td>rented</td>
<td>A level or equiv</td>
</tr>
<tr>
<td>Amy</td>
<td>24</td>
<td>7</td>
<td>With partner</td>
<td>rented</td>
<td>first degree or equiv</td>
</tr>
<tr>
<td>Edward</td>
<td>30</td>
<td>7</td>
<td>Alone</td>
<td>bought or on mortgage</td>
<td>higher degree</td>
</tr>
<tr>
<td>Kieron</td>
<td>29</td>
<td>7</td>
<td>Alone</td>
<td>rented</td>
<td>none</td>
</tr>
<tr>
<td>Oliver</td>
<td>26</td>
<td>7</td>
<td>With parent</td>
<td>rented</td>
<td>none</td>
</tr>
<tr>
<td>Cecile</td>
<td>26</td>
<td>8</td>
<td>With parent</td>
<td>missing (mortgage)</td>
<td>first degree or equiv</td>
</tr>
<tr>
<td>Jon</td>
<td>27</td>
<td>8</td>
<td>Alone</td>
<td>bought or on mortgage</td>
<td>higher degree</td>
</tr>
<tr>
<td>Alice</td>
<td>24</td>
<td>9</td>
<td>With parent</td>
<td>bought or on mortgage</td>
<td>first degree or equiv</td>
</tr>
<tr>
<td>Eugene</td>
<td>27</td>
<td>9</td>
<td>With parent</td>
<td>bought or on mortgage</td>
<td>GCSE</td>
</tr>
<tr>
<td>Lucy</td>
<td>27</td>
<td>9</td>
<td>With partner</td>
<td>rented</td>
<td>GCSE</td>
</tr>
<tr>
<td>Lyn</td>
<td>19</td>
<td>9</td>
<td>With parent</td>
<td>bought or on mortgage</td>
<td>A level or equiv</td>
</tr>
<tr>
<td>Petra</td>
<td>30</td>
<td>9</td>
<td>With partner</td>
<td>bought or on mortgage</td>
<td>GCSE</td>
</tr>
<tr>
<td>Daniel</td>
<td>26</td>
<td>10</td>
<td>With partner</td>
<td>rented</td>
<td>GCSE</td>
</tr>
<tr>
<td>Jude</td>
<td>22</td>
<td>10</td>
<td>With parent</td>
<td>bought or on mortgage</td>
<td>A level or equiv</td>
</tr>
<tr>
<td>Marc</td>
<td>30</td>
<td>10</td>
<td>Alone</td>
<td>rented</td>
<td>higher degree</td>
</tr>
<tr>
<td>Tanya</td>
<td>28</td>
<td>11</td>
<td>With friends</td>
<td>rented</td>
<td>first degree or equiv</td>
</tr>
<tr>
<td>Anna</td>
<td>28</td>
<td>12</td>
<td>With friends</td>
<td>bought or on mortgage</td>
<td>first degree or equiv</td>
</tr>
<tr>
<td>James</td>
<td>16</td>
<td>12</td>
<td>With parent</td>
<td>rented</td>
<td>GCSE</td>
</tr>
<tr>
<td>Jerry</td>
<td>25</td>
<td>12</td>
<td>With partner</td>
<td>rented</td>
<td>A level or equiv</td>
</tr>
<tr>
<td>Matt</td>
<td>24</td>
<td>14</td>
<td>With parent</td>
<td>missing</td>
<td>A level or equiv</td>
</tr>
<tr>
<td>Carmen</td>
<td>24</td>
<td>15</td>
<td>With parent</td>
<td>got mortgage with fiancé</td>
<td>first degree or equiv</td>
</tr>
<tr>
<td>Mario</td>
<td>28</td>
<td>15</td>
<td>With parent</td>
<td>bought or on mortgage</td>
<td>A level or equiv</td>
</tr>
<tr>
<td>Wayne</td>
<td>20</td>
<td>15</td>
<td>With parent</td>
<td>missing (mortgage)</td>
<td>GCSE</td>
</tr>
<tr>
<td>Marian</td>
<td>19</td>
<td>16</td>
<td>With parent</td>
<td>bought or on mortgage</td>
<td>A level or equiv</td>
</tr>
<tr>
<td>Millie</td>
<td>26</td>
<td>16</td>
<td>Alone</td>
<td>rented</td>
<td>GCSE</td>
</tr>
<tr>
<td>Raj</td>
<td>22</td>
<td>16</td>
<td>With parent</td>
<td>bought or on mortgage</td>
<td>A level or equiv</td>
</tr>
<tr>
<td>Ajay</td>
<td>28</td>
<td>17</td>
<td>With parent</td>
<td>bought or on mortgage</td>
<td>first degree or equiv</td>
</tr>
<tr>
<td>Hanna</td>
<td>18</td>
<td>17</td>
<td>With parent</td>
<td>bought or on mortgage</td>
<td>A level or equiv</td>
</tr>
<tr>
<td>Samuel</td>
<td>28</td>
<td>17</td>
<td>Alone</td>
<td>bought or on mortgage</td>
<td>higher degree</td>
</tr>
<tr>
<td>George</td>
<td>29</td>
<td>18</td>
<td>With parent</td>
<td>bought or on mortgage</td>
<td>GCSE</td>
</tr>
<tr>
<td>Luc</td>
<td>24</td>
<td>18</td>
<td>With parent</td>
<td>bought or on mortgage</td>
<td>A level or equiv</td>
</tr>
<tr>
<td>Henry</td>
<td>30</td>
<td>19</td>
<td>Alone</td>
<td>rented</td>
<td>GCSE</td>
</tr>
<tr>
<td>Laura</td>
<td>30</td>
<td>19</td>
<td>With parent</td>
<td>bought or on mortgage</td>
<td>GCSE</td>
</tr>
<tr>
<td>Gus</td>
<td>25</td>
<td>19</td>
<td>With parent</td>
<td>bought or on mortgage</td>
<td>first degree or equiv</td>
</tr>
</tbody>
</table>

(Survey Qs 1d, 1e, 3)
Table 57 Monthly earned income range by name, interviewees' survey data

<table>
<thead>
<tr>
<th>Monthly earned income range</th>
<th>Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>More than £2000</td>
<td>M: Ajay, Samuel; F: Anna</td>
</tr>
<tr>
<td>£1501-2000</td>
<td>M: Daniel; F: Tanya</td>
</tr>
<tr>
<td>£1000-1501</td>
<td>M: Jerry, Jon, Jude, Marc, Mario; Lucy, Millie</td>
</tr>
<tr>
<td>£501-1000</td>
<td>M: Edward, Eugene, Luc, Matt, Satish; F: Carmen, Sara</td>
</tr>
<tr>
<td>Less than £501</td>
<td>M: Gus, James; F: Cecile, Hanna, Marian</td>
</tr>
<tr>
<td>None</td>
<td>M: Henry, Kieren, Luther, Raj, Tristram, Wayne; F: Amy, Debra, Kelly, Lyn, Petra.</td>
</tr>
<tr>
<td>Missing data/NA</td>
<td>M: Ben, George, Oliver; F: Alice, Laura</td>
</tr>
</tbody>
</table>

Note: Wayne obtained a part time job between the survey and his interview.

(Survey Q 4c)