

Recipients' Experiences of Living-Related Renal Transplantation

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School of Psychology – Clinical Section

Faculty of Medicine

University of Leicester

Anna Symonds

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Statement of Originality

I confirm that this is an original piece of work.

The literature review and research report
contained within this thesis have not been submitted
for any other degree, or to any other institution.

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Thesis Abstract: Recipients' Experiences of Living-Related Renal Transplantation

Author: Anna Symonds

Literature Review.

This section critically reviewed and critiqued existing literature on the psychological impact of living-related renal transplantation and its precursors. A semi-structured narrative review of the literature was informed by a theoretical framework (Moos & Schaefer, 1984). The review found clear evidence for the psychological impact of living-related renal transplantation and its precursors. However, a number of methodological issues were identified. The literature review observed a lack of research examining recipients' perspectives of their experiences. Recommendations for the exploration of experiences of living-related renal transplantation from recipients' own positions and understanding were made.

Research Report.

Objectives: The research report aimed to explore the experiences of living-related renal transplant recipients.

Method: An interview design using a self-selecting sample was adopted. Semi-structured interviews were undertaken with eight individuals who had each received a kidney from a living-related donor within the last nine years. Transcribed interviews were analysed using Interpretative Phenomenological Analysis (IPA).

Results: Analysis of transcribed interviews identified a total of twenty subordinate themes, reflective of participants' experiences. From this, five super-ordinate themes were elicited: story of illness, kidney as a gift, uncertainty about the future, coping mechanisms and liberty.

Conclusions: Generated themes provide insight for health professionals working in the field of renal medicine. Clinical practice should consider the use of pre-operative information and education, systemic working between health professionals and post-transplant care facilities. Further research is required to assess the progression of psychological processes over time.

Critical Appraisal.

The critical appraisal aimed to provide a detailed critique of the research process and methodology. It details a personal account of the research and considers learning points to inform future practise.

Word Count: 256

Section A

Literature Review

**The Psychological Impact of Living-Related Renal
Transplantation and its Pre-cursors**

To be submitted to The British Journal of Health Psychology (see Appendix A for guidelines).

Word Count (excluding references): 7996

**Abstract: The Psychological Impact of Living-Related Renal
Transplantation and its Pre-cursors**

Objectives. The aims of this paper were to review and critique existing research literature on the psychological impact of living-related renal transplantation and its precursors.

Design. The paper is a semi-structured narrative review of the available literature, informed by current theoretical frameworks emerging in health psychology.

Methods. Literature for this review was obtained using the major health and social science electronic databases Medline, PsychINFO, Embase and Web of Science.

Results. Eighty-one studies were identified. Whilst there was clear evidence for the psychological impact of living-related renal transplantation and its precursors, problems with the research include: cultural differences, variety of measures used, lack of methodology reporting, fragmentation of the experience and over reliance on quantitative methods.

Conclusions. The research presents the appraisal, adaptation and coping process involved in living-related renal transplantation. The review identifies a significant gap in the literature, namely the lack of research which takes into account recipients' own perspectives of their experiences. Conducting research in this area is likely to provide greater understanding and more accurate representation of experiences with living-related renal transplantation.

Word Count: 175

1.0 Introduction to the Literature Review

This section commences with an introduction to living-related renal transplantation and the psychological impact and processes involved in the procedure. The prevalence and psychological impact of kidney disease is then presented, followed by consideration of the psychological impact of cadaveric transplantation. A detailed introduction is provided prior to the objectives of the literature review in order to offer relevant context and background to the reader. The objectives of the review and the implemented search strategy are stated, followed by the introduction of a theoretical framework used to provide a useful structure for the review. A review of the psychological impact of living-related renal transplantation and its pre-cursors is presented, proceeded by a summary of the literature and identification of methodological issues and ideas for future research.

1.1 Living-related renal transplantation

The number of living-donor renal transplants being performed in the UK is increasing, with a rise of 30% between 1997 (121 transplants) and 1998 (181 transplants) (UKTSSA, 1998). Rates of survival are higher than cadaveric kidney transplant, and confer significantly reduced risks to the donor (Betram *et al.* 1995). Transplant centres have considered such donation viable at a time when the procedure appears more ethically acceptable (Spital, 1994). Virtually all American transplant centres now use living-related renal donation despite previous oppositions and concerns relating to non-

maleficence (doing no harm) for the donor and beneficence (doing good) for the recipient (Spital, 1994).

As medical advancements improve the procedure of living-related renal transplantation, there is a growing body of literature regarding its psychological impact. This is arguably distinct from the impact of cadaveric and living-unrelated transplantation, described briefly above, due to the uniqueness of the procedure. It is these differences which make researching the experiences of living-related recipients more challenging and distinct.

1.1.1 Psychological impact and processes of living-related renal transplantation

When a kidney transplant is required, an entire family is affected. Under crisis conditions, one or more family members must decide to give or receive a kidney, often negatively influencing the dynamic of the family relationship (Simmons *et al.*, 1971). Examination of the psychological impact of donating on the family process, highlighted families' decision-making processes, levels of stress and conflict, and communication patterns (Simmons *et al.*, 1987). The findings focused upon positive feelings engendered in the donation, and the complexities of the gift relationship when relatives did not wish to donate an organ. Positive feelings and ties of closeness and life appreciation were often experienced. Donors' perceptions were influenced by the perceived health status of the recipient family member, ambivalence, gender and self-

esteem. Donor ambivalence increased when role conflict increased, and after transplant, negative self-esteem of donors correlated with negative feelings about donation.

Gibson's (1996) review of the literature about factors which influence organ donation suggests that there are differences between giving an inanimate object and a human organ. These include the lack of freedom of giving and receiving related factors in the process of acquiring a kidney, and the impossibility of returning the gift. Whether the organ donation is perceived as a gift or not, it is valuable to determine the meaning of the donation to the donor and the recipient (Gibson, 1996).

Recipients due to failing health, tend to be forced into a dependent role (Weizer *et al.*, 1989). Depression, dependency, anger and suicidal thoughts are some of the responses a recipient may experience (Weizer *et al.*, 1989). Denial is often used as a defence against these feelings, resulting in recipients' refusal to see themselves as sick (Murray *et al.*, 1999). Murray *et al.* (1999) found that sixty percent of recipients had never talked to anyone about their feelings, and eighty percent had refused to consider a transplant from a family member.

The process of living-related renal transplantation begins with the onset of kidney disease. The prevalence and psychological impact of this is discussed.

1.2 Kidney disease

The National Service Framework for Renal Services (Department of Health, 2005) reports the prevalence of diagnosed chronic kidney disease to be 5,554 per million population (John *et al.*, 2004). Chronic kidney disease is a long-term condition, potentiated by a number of pathological processes which ultimately involve damage or abnormality in both kidneys and loss of kidney function (Department of Health, 2005). Approximately 5% of those with kidney disease develop end stage renal failure, many being elderly, and co-morbidity is common. Twenty-five percent of those with end stage renal failure have diagnosed diabetes, and three quarters have a history of hypertension (Coresch *et al.*, 2003). Since the kidneys' primary role is one of blood purification and homeostasis, kidney disease can be fatal without dialysis or a kidney transplant (Department of Health, 2005). A chronic, life threatening condition, the psychological impact can be significant (Balinsky, 2000).

1.2.1 Psychological impact of living with chronic renal disease

For the purpose of this review, the term chronic renal disease will be used to incorporate the full spectrum of the manifestation of the disease, including end stage renal failure (Darbyshire *et al.*, 2006). Psychological distress has found to be highly prevalent within chronic renal disease patients (Kimmel *et al.*, 1998) and has been found to contribute to greater morbidity and mortality in the population (Finkelstein & Finkelstein, 2000). The predominant areas which form the focus of the psychological

impact of living with chronic renal disease literature are namely psychological adjustment, psychological distress and coping.

Patients living with chronic kidney failure must cope with the threat of death, reduced life expectancy, lessening physical strength, and an often intrusive medical regime (Will & Johnson, 1994). Evidence suggests that psychological distress in chronic renal failure patients is reduced when the patients' style of coping is consistent with the demands of the treatment they are receiving (Christensen & Ehlers, 2002). It is also affected by the coping process they adopt, namely how they evaluate stress (appraisal) and what coping resources they have (Wright *et al.*, 1999). Lazarus and Folkman (1984) classify strategies as problem or emotion focused. Problem focused coping has been found to be more effective than emotional coping in terms of emotional reactions and performance levels when coping with kidney failure (Zeidner, 1995).

Studies which have examined coping measurements and psychological distress have found parallel relationships between the variables. Carver *et al.* (1993) found that acceptance of a disease and the use of humour predicted lower psychological distress, whereas denial predicted more psychological distress. Psychological distress in the form of depression has been regarded as the most common psychological reaction to chronic renal disease (Kimmel, 2001). It has been associated with the multiple losses which accompany the disease including the loss of role within family and social settings, loss of mobility, renal function, sexual function and cognitive abilities (Kimmel *et al.*, 1993). In addition, the symptoms of illness and the pathophysiologic

responses which are produced by a chronic and debilitating disease may cause depression (Kimmel, 2002). A gruelling regime of dialysis has been linked to psychological distress due its effects on quality of life (Molzahn, 1991) and feelings of despair (Martin-McDonald, 2003). The stressors associated with the disease, as well as its treatment, might increase the risk of developing or exacerbating depression (Kimmel, 2002).

The processes which result in the presence of psychological distress or in successful adaptation to the disease have been explained by models of mental adjustment. Moorey and Greer's (1989) model focuses on the appraisal, interpretation and evaluation of the illness made by patients, which determines their emotional and behavioural reactions. A cognitive trial involved in the process consists of a negative view of the diagnosis, control of the disease and prognosis. Five common adjustment styles emerge from the process. Each represents a different way of viewing the threat to survival: fighting spirit, fatalism, denial, anxious preoccupation and helplessness/hopelessness. Mental adjustment characterised with fighting spirit is associated with better psychological adjustment (Schnoll *et al.*, 1998). Mental adjustment representative of helplessness/hopelessness, anxious preoccupation, and fatalism is associated with high psychological distress (Grassi *et al.*, 1993). Denial, however, is not linked to psychological distress (Watson *et al.*, 1991). The purpose of kidney transplantation as a therapy is to dramatically improve a patient's health, therefore decreasing psychological distress and strengthen general adjustment level (Simmons *et al.*, 1977).

1.3 Cadaver transplants

Kidney transplant using a cadaver organ, i.e. from a dead non-heart beating body, is generally accepted as optimal treatment for the majority of patients with chronic kidney disease (Griva *et al.*, 2002). The transplantation of a healthy kidney aims to remove the patient from the status of being sick as well as eliminating the need for dialysis. The benefits have been described in terms of better quality of life (Cameron *et al.*, 2000) and prolongation of life (Schunelle *et al.*, 1998).

1.3.1 Psychological impact of cadaver transplants

Quality of life is defined as: the patients' feelings of physical well being, their psychological well-being including their level of happiness and anxiety, the tendency to psychiatric symptomatology, social and interpersonal adjustment and vocational rehabilitation (Simmons *et al.*, 1977). Studies have demonstrated dramatic improvements in quality of life in cadaveric kidney transplant recipients, compared to pre-transplant period (Hathaway *et al.*, 1998; Jofre *et al.*, 1998). However, a small proportion report less favourable outcomes. These recipients tend to experience kidney rejection or severe infection, which are associated with a lower level of psychological well-being (De Geest & Moon, 2000). The constant threat of rejection, the uncertainty of long-term prognosis and the psychological acceptance of a body-part from an unknown donor, are also potential sources of distress for recipients (Simmons *et al.*,

1977). After years of assuming the dependent role of invalid, some kidney transplant patients have difficulty resuming an independent role (Idelson *et al.*, 1974).

Survivor guilt directly after transplant has been associated with grief reactions (Craven *et al.*, 1987), with recipients describing overwhelming feelings of sadness and loss for the unknown donor (Baines *et al.*, 2002). Current practice in the UK prohibiting direct contact between cadaver recipients and donor families can cause frustration to those who wish to express their gratitude and therefore reduce feelings of guilt (Vamos, 1997).

Recent years, however, have seen both an increase in patients waiting for a renal transplant and a corresponding drop in the number of cadaveric donor transplants within the same period (United Kingdom Transplant Support Service Authority (UKTSSA), 1998). There are a number of reasons for the shortage of kidneys for donation. Organs are usually sourced from road traffic accidents. Seat belt legislation, drink-driving regulations, safety initiatives, and improved car design, have all contributed to a fall in the number of fatalities (UKTSSA, 1995). This has been paralleled by a reduction in the number of deaths from intracranial haemorrhage, another principal source of donated organs, due to improved treatments (Jakobsen, 1995). The shortage of kidneys from cadaveric donors, and a lack of alternative sources, has created increased interest in living-related donors (Spital, 1993).

Due to the uniqueness of living-related transplantation and the disparities which exist between cadaver, living-unrelated and living-related transplantation, the following review will allow for focused exploration of the psychological impact of living-related renal transplantation.

1.4 Objective of the literature review

The objective of this paper is to provide a semi-structured narrative review of the available literature on the psychological impact of living-related renal transplantation and its precursors informed by current theoretical frameworks emerging in health psychology. Psycinfo, Medline, Embase and Web of Science were searched for relevant articles from 1954 to 2006.

The key search terms were: living-related kidney transplant; precursor; renal; kidney; outcome; adjustment; adaptation; quality of life; affect; anxiety; depression; mood; stress; coping. Articles were included if they met the following criteria: sourced from a peer-reviewed journal, clearly measured psychological impact and outcomes, included only living-related kidney recipients. Additionally, the article must have been available in English. Reports of research with children were not included. Eighty-one articles were thus included within this review. For a summary of studies, see Appendix B.

The aims of the paper were to systematically review studies regarding the psychological impact of living-related renal transplantation to:

- Provide an overview of the research quality
- Identify further research needs in the area.

1.5 Theoretical Framework

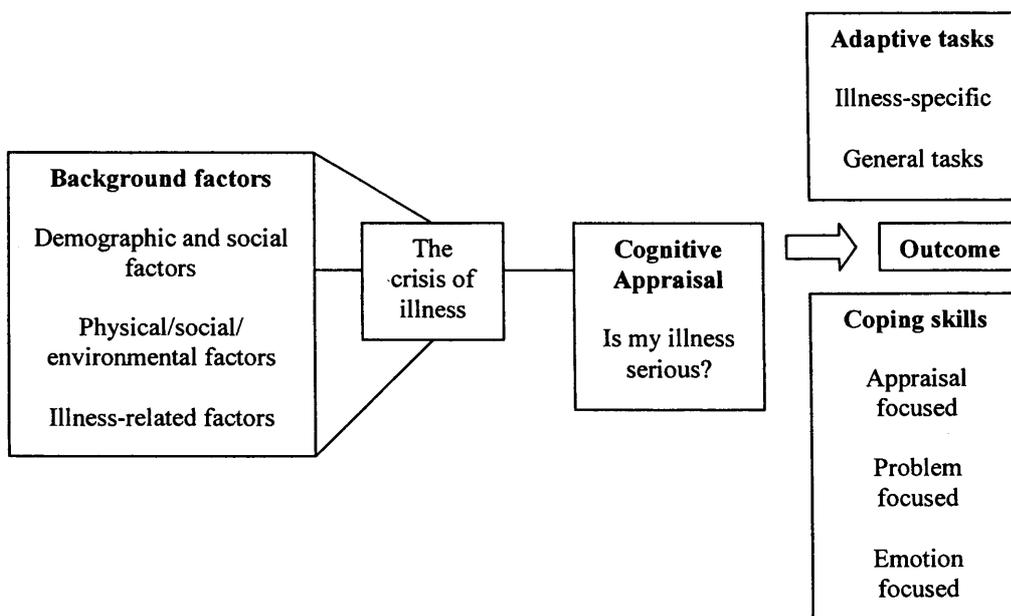
The majority of papers offer no explicit theoretical base, which can be problematic when empirical research aims to ground interventions within conceptual bases. This review is therefore based around a theoretical framework in order to integrate findings and to identify both researched and neglected areas.

The framework used to provide a useful structure for the review is crisis theory (Moos & Schaefer, 1984, Figure 1). It is used to examine how people cope with major crises and transitions, and has provided a framework for understanding the impact of illness of injury. It examines the effect of disruption on personal and social identity, and suggests that psychological systems are aimed at maintaining equilibrium. Within this framework, individuals are self-regulators and will return to a stable state.

Moos and Schaefer (1984) argue that illness can be considered a crisis as it represents a turning point in an individual's life. They suggest that physical illness causes a variety of changes in identity, role, social support and the future. The crisis of illness may also be exacerbated by factors which are specific to illness including the unpredictability of the illness, having unclear information, limited prior experience of

the illness and the need to make a decision quickly. Figure 1 illustrates the process for coping with these factors.

Figure 1: Coping with the crisis of illness (Moos & Schaefer, 1984).



For the purpose of this review, the crisis of illness is considered to be the need for a living-related renal transplant. Although many recipients may not describe the need for the procedure of transplantation as a crisis, with many positive expectations existing regarding the transplant, research suggests that many recipients experience the pre-transplantation to be a stressful and psychologically disturbing time (Baines *et al.*, 2002; Heck *et al.*, 2004).

The components of the model will be explained in further detail during its use as a theoretical framework to review the literature regarding the psychological impact of living-related renal transplantation and its pre-cursors.

2.0 The Psychological Impact of Living-Related Renal Transplantation and its Pre-cursors: A Review of the Literature

2.1 Background Factors

Moos and Schaefer (1984) suggest that the consideration of background factors is relevant to the way in which individuals cope with the crisis of illness. Demographic and social factors such as age, gender, marital status and role within the family have been considered to be influential. Physical, social and environmental factors including mobility, independence and role within the community are also argued to be important. Also of relevance are illness-related factors such as the cause of renal failure and time since kidney failure.

2.1.1 Demographic factors

A range of demographic variables have been reported in the studies within this review, including age, gender and marital status.

2.1.1.1 Age

Although studies provide an age range and mean age of participants, their justification for use of these ranges is rarely explained. Many studies do not reflect upon the potential impact of age during discussion of their findings. Some studies, however, have focused on the impact of age in renal failure (Robello *et al.*, 2001). In this study, the effects of renal failure, health related quality of life, age and gender were examined in patients undergoing haemodialysis, and those who had received a transplant of either cadaveric or living-related origin. Elderly renal transplant patients (over sixty-five years old) rated quality of life higher than in the general population, and when compared to those below sixty-five years of age. Quality of life, measured using a questionnaire designed by the authors, was also higher in transplant recipients than those receiving haemodialysis.

In contrast, some authors have found few differences between renal transplant patients aged over and under sixty-five years (Hestin *et al.*, 1994), nor between the general population and recipients (Benedetti *et al.*, 1994). Pucheu *et al.* (2004) noted that younger participants with end stage renal failure were healthier and better adjusted than older participants. Discrepancies for these findings may be due to differences in measuring outcomes, with no standard method employed across the studies.

2.1.1.2 Gender

The role of gender in living-related transplant and end stage renal failure is not yet firmly established. Some research suggests that women with end stage renal failure report more physical symptoms (Lindquist *et al.*, 1998; Mittal *et al.*, 2001). Women have also been found to have poorer quality of life (Rocco *et al.*, 1997), adjustment and increased psychological problems (Reiss & De-Nour) and lower life satisfaction (Iacovides *et al.*, 2002). Conversely, studies have found that women are healthier and better adapted than men (House, 1987). Keogh & Freehally (1999) found no significant differences in health difficulties and acceptance of illness between males and females. These studies, however, use a variety of measures, some of which are designed by the authors. The validity and reliability of these is therefore questionable. Sample sizes also vary, from 15 (Mittal *et al.*, 2001) participants to 1,284 (Rocco *et al.*, 1284).

2.1.1.3 Marital status

Studies examining the role of marital status have elicited variable findings. Marital status has been associated with better adaptation and lower depression scores in renal transplant recipients compared to those on dialysis (Akman *et al.*, 2004). The authors consider that spouses may adapt to the illness more quickly, and therefore provide support for their partners. Other research has found no relationship between marital status and psychosocial outcome of illness (Auer *et al.*, 1990; Pucheu *et al.*, 2004). It has been suggested that the impact of marital status has been considered too

simplistically (Binik *et al.*, 1990). A number of assumptions are made from marital status. For example, if one is married, it is assumed that the individual has a degree of support. However, this may not necessarily be the case as marital status does not account for the nature of the relationship, but instead assumes this from the label selected.

2.1.2 Physical, social and environmental factors

Background factors also involved in coping with the crisis of illness as suggested by Moos and Shaefer (1984) include physical, social and environmental aspects.

2.1.2.1 Health

Existing research suggests that the role of health and its impact on an individual is varied. Health has significantly been related to quality of life and depression (Weisbord & Palevsky, 2005). However, psychosocial outcomes have also been found to be unrelated to health (House, 1987).

A number of factors have been related to health, such as self-efficacy, displayed for example as adherence to medication (Lev & Owen, 1998). Beliefs about health such as those regarding the power oneself has over health, have been associated with the impact of health on physical and psychosocial outcomes (Pucheu *et al.*, 2004). Compared to

those receiving dialysis, renal transplant recipients are healthier than those on dialysis (Niu & Li, 2005).

2.1.2.2 Social support

Studies examining social support either fail to operationalise the construct or are oblique in referencing definitions. Patel *et al.* (2005) view it as a concept which recognises that patients live within networks through which they can receive and give help, and engage in social interactions. As such, social support can be obtained from family, friends, colleagues or members of the community. Several studies have demonstrated that social support is associated with improved outcomes and improved survival rates in chronic illnesses including end stage renal failure (Patel *et al.*, 2005). It has been identified as providing a role as a guard against psychological distress when experiencing illness (Burton *et al.*, 1988), as well as assisting compliance, improved access to healthcare, improved psychosocial and nutritional status, and decreased stress levels (Patel *et al.*, 2005).

However, the mechanisms by which social support influences psychosocial outcomes are lacking. Syminster and Friend (2003) argue that social support operates to enhance self-esteem, which mitigates depression and elevates optimism. However, the focus upon spousal relationships has been criticised for its lack of consideration of other support such as friendship, community and religious groups. Community support has been shown to have a positive impact on recovery from stroke (Glass *et al.*, 1993).

Friendship and spiritual practice have a significant effect on recovery of ill health, particularly for women (Daniell, 2003).

2.1.2.3 Work

The percentage of individuals with end-stage renal failure currently working varied from 3% to 56% in this review. Dialysis is a recognised illness-induced barrier to working (Oldenburg *et al.*, 1988) However, Reynolds *et al.* (1993) noted that individuals with end-stage renal failure have significantly fewer qualifications and increased levels of unemployment compared to matched controls.

2.1.3 Illness-related factors

Moos and Schaefer (1984) suggest that illness-related factors contribute to the background information which further influences how individuals cope with the crisis of illness. According to Moos and Schaefer's (1984) model, illness-related factors precede the crisis of illness. For the purpose of this review, the crisis of illness is considered to be the imminent need for the transplant. On this basis, many potential recipients may be diagnosed with end-stage renal failure, and therefore the cause and time since renal failure and mode of dialysis, are considered background factors to the crisis of having a living-related renal transplant.

2.1.3.1 Cause of renal failure

The most common causes of end stage renal failure are polycystic kidney disease, nephritis, congenital kidney disease, hypertension and diabetes (Cameron, 1996). Being unaware of the cause has been related to poor quality of life (Frank *et al.*, 2003). The cause, however, of renal failure has been related to acceptance to illness (Keogh & Freehally, 1999). Individuals with polycystic kidney disease score significantly higher on acceptance of illness scales than those with end stage renal failure as a result of diabetes or hypertension (Keogh & Freehally, 1999). This could be explained by those with polycystic kidney failure being aware of their condition in their teens, whereas end stage renal failure generally develops around the age of fifty years. Having extended time to consider and prepare for dialysis may assist acceptance of its consequences.

2.1.3.2 Time since renal failure

Time since diagnosis of end-stage renal failure may be relevant when examining illness-related factors. Research examining the impact of time since diagnosis on psychological functioning is ambiguous. Several studies argue that time since onset is not predictive of psychological change (Martin & Thompson, 2000; Pucheu *et al* 2004). However, psychological distress has been found to reduce according to time lapsed since diagnosis (Craven *et al.*, 1987; House, 1987). Craven *et al.* (1987) suggest that the passage of time allows dialysis patients to adapt to the stressors related to their

illness. Depression is also considered to become less common as with increasing duration of dialysis (Kutner *et al.*, 1985).

2.1.3.3 Mode of dialysis

A hierarchy has repeatedly been identified for preferred treatment for end stage renal failure by patients. Transplantation is the preferred treatment for them (Merkus *et al.*, 1999) followed by home and then hospital dialysis (Auer *et al.*, 1990). This is due to the physical symptom burden of itching and fatigue, as well as the psychological effects of dialysis stress (Martin-McDonald, 2003). However, comparative studies of the modalities of dialysis could be criticised for their lack of consideration of pre-dialysis variance in health, demographic and psychosocial characteristics, which may be responsible for reported differences in dialysis modalities. Studies measure the burden of dialysis using a number of methods such as time taken to dialyse or number of sessions, resulting in varying, unreliable findings.

2.2 Cognitive Appraisal

Once confronted with the need for a transplant, Moos and Schaefer (1984) describe three processes which constitute the coping process: cognitive appraisal, adaptive tasks and coping skills. This section will review the literature regarding the cognitive appraisals which occur during living-related renal transplantation. The framework will be used to provide a structure for the consideration of cognitive appraisal.

Cognitive appraisal is important in the psychological adjustment to illness and transplantation (Devins *et al.*, 1997). At a stage of disequilibrium triggered by the need for a transplant, potential recipients will initially appraise the seriousness and significance of the transplant. Moos and Schaefer (1984) consider that factors such as knowledge, previous experience and social support may influence this appraisal process. Illness cognitions are particularly relevant at this time and relevant to the coping process, as they are related to how an illness will be appraised.

Studies have identified that potential renal recipients refuse to believe themselves to be sick or near death (Murray *et al.*, 1999; Simmons *et al.*, 1987). This denial of health status is commonly reported within end stage renal failure patients, identified as a defense against feeling, as well as a mechanism for coping with thoughts regarding illness and death (Short & Wilson, 1969). White *et al.* (1990) consider that this belief serves to protect the family member from the decision of whether to donate.

The family dynamic of a balance between change and stability is in effect when a family member requires a transplant. To maintain family emotional equilibrium and status quo, potential recipients do not ask relatives for a kidney (Conrad & Murray, 1999). When a potential recipient asks a family member to donate, significant role changes and disruptions are likely to occur within the family (Wright & Leahey, 1994). In a review of the literature, Conrad and Murray (1999) report that 80% of potential recipients refuse to consider a transplant from a family member due to beliefs of failure formed from anecdotal tales of unsuccessful transplantation.

Between seven and twenty percent of donors post-donation believe that they were coerced (Hilton & Starzomski, 1994). Beliefs regarding a sense of obligation towards the recipient, combined with feelings of guilt often influence the decision to donate. Societal attitudes, previous relationships towards the recipient, and the donor's motives affect decisions in giving or refusing to donate a kidney. Religious beliefs, perceived medical risks and cultural background are also relevant (Hilton & Starzomski, 1994).

A number of studies have examined the role of beliefs about the self when preparing for transplant, including a range of related concepts such as illness representations, perceived control, self-efficacy and self-regulation. Self-regulatory beliefs are important and moderated by current mode of dialysis as well as hopes for future transplant (Christensen *et al.*, 1994). Perceived control has been found to be particularly influential in chronic illness research due to its impact on adherence to medical regime and mood. Locus of control describes the extent to which an individual believes that certain outcomes are due to their own, others' behaviour or chance. Devins *et al.* (1982) and Krause and Stryker (1984) provided evidence for the role of perceived locus of control in adjustment to chronic illness and treatment. However, these have been criticised for neglecting beliefs about the role of health professionals in controlling illness. Health locus of control is developed from this research, and refers to the belief that health is determined by one's own behaviour or by the behaviour of others, for example medical staff. Believing that one has both the practical and emotional resources to cope with the illness and changes has been associated with good psychological outcome (Tsay & Healstead, 2002). High self-efficacy is predictive of

better psychological adjustment and compliance to treatment (Tsay & Hung, 2004).

Christensen *et al.* (1991) found that beliefs in personal control were generally related to good adjustment to illness and the impending transplant, whereas a belief in control by others was related to adjustment only in those with good prognoses.

2.3 Adaptive tasks

Following cognitive appraisal, Moos and Schaefer (1984) describe adaptive tasks that are used as part of the coping process. These are divided into illness specific tasks and general tasks and for the purpose of this review, these will be considered within the context of post living-related renal transplantation.

2.3.1 Illness related tasks

Illness related tasks deal with pain, treatment procedures and relationships with medical staff. Health related quality of life is a concept which incorporates these factors, defined as the capacity to perform social and domestic roles in order to meet the challenges of everyday living without emotional distress or physical disability (Forsberg *et al.*, 1999). It acknowledges the role of medical staff in improving or maintaining health. A common way to explore quality of life after renal transplantation is to identify problems associated with the type of transplantation, and not quality of life in general (Forsberg *et al.*, 1999).

Although living-related renal transplantation is now a commonplace procedure, with a death rate of less than 1%, a number of post-operative complications can occur (Tinley & Guttman, 1997). Due to immunosuppression, susceptibility to infection increases (Cameron, 1996). The body's immune system is likely to attack the kidney severely, potentially resulting in removal of the kidney (Cameron, 1996). However well a recipient feels, they are always aware of the threat of rejection and the possible return to dialysis (Simmons *et al.*, 1977). When kidney function is excellent and the recipient is discharged from hospital, the post-transplant medical regime can be stressful. Recipients are reliant on health professionals to monitor their health and medication, resulting in feelings of loss of control and dependence (Christensen *et al.*, 1990). Hospital visits three times a week immediately following transplant can interfere with daily life. However, compared to liver and heart recipients, the medical regime following transplantation least affects kidney recipients in their daily life (Forsberg *et al.*, 1999).

Bodily pain is an underestimated problem after transplantation, which can be an obstacle to quality of life (Hellgren *et al.*, 1998). Several studies have reported severe pain, restriction of movement and musculoskeletal pain in kidney transplant recipients (Jagose *et al.*, 1997; Naredo-Sanchez *et al.*, 1994). Severe pain has been identified as occurring 50% of patients who had received a kidney transplant between six and twenty-four months previously (Forsberg *et al.*, 1999). Severe pain affects daily living, limits physical functioning, vitality and general health (Hellgren *et al.*, 1998). When comparing the 36-Item Short Form Health Survey (Ware & Sherbourne, 1992), general

health, general quality of life, anxiety and depression in renal recipients with and without pain, significant differences were found in the areas of general health, physical and social functioning and bodily pain (Forsberg *et al.*, 1999). Recipients with pain were found to score more highly in the area of depression than those without pain (Bryan *et al.*, 1998).

2.3.2 General tasks

General tasks serve to preserve emotional balance, preserve a satisfactory body image and prepare for the uncertainty of the future. Many of the tasks have been studied specifically within living-related renal populations, and this research is presented.

Much research has been conducted regarding the emotional impact of living-related renal transplantation, particularly on mood (Akman *et al.*, 2004; Tanriverdi *et al.*, 2004). The incidence of depression among living-related recipients is estimated to be between 20% and 25% (Akman *et al.*, 2004), which is slightly higher than within the general population (Fennell, 2002). Loss of renal function, role within family and society, cognitive abilities, physical abilities and sexual function have been identified as the main causes of depression in living-related renal recipients (Rocha *et al.*, 2001). Symptoms commonly found in depressed recipients include low mood, changes in appetite, sleep disturbance, anhedonia, concentration difficulties and feelings of guilt, worthlessness, hopelessness and helplessness (Tanriverdi *et al.*, 2004). Frazier *et al.*

(1994) speculate that depression reduces self-esteem, leading to noncompliance with therapy and potentially affecting kidney graft and recipient survival.

Also linked to low mood is body image, which requires preserving in order to maintain mastery and control (Moos & Schaefer, 1984). Body image has been examined across the process of organ donation, however, it is a widely used but poorly defined term (Newell, 1991), with little consensus about its definition. Van Der Valde (1985) considers that body image incorporates a broad spectrum of dimensions including thoughts, feelings, perceptions and behaviours related to the various aspects of the body. The notion has become a focus and conceptual filter applied to the reactions to living-related renal transplantation.

Bodily changes which occur include muscle wasting, a redistribution of fat around the body and facial fat, caused by steroids (Cameron, 1996). Acne and hair loss are also commonly reported (Cameron, 1996). Altered body image has been identified as a main stressor after a successful transplant (Fallon *et al.*, 1997), and has been associated with depression and anxiety (Schover, 1991). Ways in which body-image can be preserved can be understood using Sanner's (2003) framework which proposes two processes: the naturalness of a transplant and the benevolent transplant. A few months post-transplant, efforts are made to normalise the transplanted body by regarding it as a natural part of the body. Its protrusion immediately after surgery, once settled, assists this process. The benevolent transplant involves avoidance of thinking about the kidney as a human body part, and instead depersonalising it. Sanner (2003) suggests that this serves as a defence

against distressing thoughts of negative body image. Typically over a two year period, the organ is accepted as a life-saving, benevolent body part.

Accompanying immediate concerns post-transplantation are worries regarding the future, and the preparation for an uncertain future (Moos & Schaefer, 1984). Concerns for the health of the living-donor and the survival of the kidney have been identified as primary sources of anxiety in living-related recipients (Baines *et al.*, 2002; Dubovsky & Penn, 1980). Expressed anxieties about the future are common (Baines & Jindal, 2003), and when symptomatic of a fear of rejection of the kidney, they are maintained by potential implications of the loss for the recipients' life (Baines & Jindal, 2003). The anxiety may also be a manifestation of the belief that recipients have little control over their body's acceptance or rejection of the kidney, or over the health of their donor (Frey, 1990). This can cause deterioration in mood, leading to medical non-compliance (De Geest *et al.*, 2001). As a result of fear of kidney rejection and in an attempt to redefine the future (Moos & Schaefer, 1984), recipients search for certainty in other aspects of their lives, planning ahead for both certainties and potential uncertainties (Baines *et al.*, 2002). This coping mechanism is one of many employed to deal with the crisis of illness.

2.4 Coping skills

Following both appraisal and the use of adaptive tasks, Moos and Schaefer (1984) describe a series of coping skills that are accessed to deal with transplantation. These

can be categorised into three forms: appraisal-focused coping, problem-focused coping and emotion focused coping. Recipients commonly use these mechanisms to assist adaptation to new circumstances, enhance feelings of control and provide relief from post-transplant anxieties (Adler, 1972). The more coping mechanisms used, the greater the degree of stress experienced by recipients (White *et al.*, 1990).

Appraisal focused coping includes attempts to understand the transplant and represents a search for meaning (Moos & Schaefer, 1984). It involves cognitive redefinition, accepting the reality of the situation and redefining it in a positive way, and cognitive avoidance and denial whereby the seriousness of the illness is minimised (Moos & Schaefer, 1984).

Denial and avoidance are common coping mechanisms used by the ill, and those recovering (Hagberg, 1974). Their presence often produces reports of restoration to health and the resolution of any negative effects of the procedure (Simmons *et al.*, 1971). The motivation to repress reality in order to minimise the severity of the illness is equally as great in pre- and post-transplant patients (Kaplan De Nour, 1968). Conversely, in order to accept and redefine the reality of their situation, recipients may focus upon the positive aspects of the transplant, such as the opportunity for a new life, or rebirth (Simmons *et al.*, 1977). It is also possible that recipients may exaggerate their pleasure with the procedure because to fail to do so would be to admit that the pain and difficulties they experienced were in vain (Simmons *et al.*, 1971). Theories of cognitive dissonance i.e. the incompatibility between two existing cognitions, would lead to this

conclusion (Festinger *et al.*, 1956). According to Helson's (1964) adaptation level theory, a person's internalised standards may shift due to life circumstances such as a transplant. When faced with a negative life event, the criteria for what is negative will be lessened. Comparisons with those who have had a successful transplant are common, which may be one way to attain a more positive view of one's own future (Lindqvist *et al.*, 1998).

Problem-focused coping involves confrontation of the problem and reconstruction of it as manageable (Moos & Schaefer, 1984). This includes seeking information, taking problem-solving action and planning events and goals that provide satisfaction (Moos & Schaefer, 1984). Emotion-focused coping involves managing emotions and maintaining emotional equilibrium (Moos & Schaefer, 1984). Efforts to maintain hope, the expression of anger and despair and resigned acceptance to the outcome occur in this style of coping (Moos & Schaefer, 1984). Research addressing these coping styles within the transplant research considers them comparatively, therefore the literature presented reflects this format.

In the cognitive theory of stress and coping (Lazarus & Folkman, 1984), coping has two major functions: problem-focused to deal with the problem that is causing the stress, and emotion-focused serving to regulate the emotional responses to the problem. Living-related renal recipients use both styles of coping, however, the older the recipient, the less emotion-focused coping used (Srivastava, 1988). Lindqvist *et al.* (1998) demonstrated that recipients more commonly implement problem-focused

approaches, rather than emotion-focused coping. Those who were more emotive in style were regarded as less well adjusted to the transplant. Greater benefits result if recipients are informed as how to best cope with their situation (Lindquist *et al.*, 1998). Palliative coping i.e. distracting oneself by doing something enjoyable such as exercising or eating or smoking more than usual, represents strategies aimed both at management of the problem and regulation of emotional responses (Jalowiec, 1991). The use of this mixed style of coping may represent efforts to achieve consolation and hold an optimistic view of life.

Female recipients, as well as females within the general population, tend to use emotion-focused, whereas men use more problem-focused coping (Ptacek *et al.*, 1992). Folkman and Lazarus (1984) stress that the problem content and the psychological appraisal of the demand may be confounding factors when interpreting gender differences. If men and women face different everyday demands, this may influence their use of coping strategies. Porter and Stone (1995) have concluded that the content of the problem experienced, rather than the gender of the individual, determines the coping strategy selected.

3.0 Summary of the Literature

A review of the impact of end stage renal disease was presented in order to provide relevant background information regarding recipients' experiences prior to transplantation. The body of research on the psychological impact of living-related

renal transplantation, also presented, has developed over time with the evolvement of medical developments. Much of the earlier research into adjustment to renal failure and transplantation was fragmented, with many studies investigating small parts of the experience of renal failure and transplantation.

Moos and Schaefer's (1984) model for coping with the crisis of illness has usefully been applied to bring together much of the diverse empirical work. The model has been used to consider background factors relevant to the crisis of end stage renal failure, including demographic, social, environmental and illness-related factors. The cognitive appraisal stage of the model presented literature regarding the psychological adjustment to both renal failure and living-related transplant. Adaptive tasks and coping skills involved in living-related transplantation were then discussed. This model allowed the literature to illustrate the process and impact of illness through to treatment.

3.1 Methodological issues

The main problems with research in this area after methodological searching of the literature include: cultural differences, variety of measures used, lack of methodology reporting, fragmentation of the experience, lack of consideration of individual differences and over reliance on quantitative methods. These have become apparent in summarising such a large body of research.

The majority of studies presented were quantitative in nature (e.g. Cameron *et al.*, 2000; Christensen & Elhers, 2002; Mittal *et al.*, 2001). Although providing a framework which values objectivity, quantification and measurement, this predominantly psychometric approach has been critiqued for simplifying the complex experience of living-related renal transplantation (Lamiell, 1995). Some of the presented studies within this review identify specific diagnostic and categorical elements of the experience of transplantation (e.g. Frey, 1990; Kimmel, 2003; Lev & Owen, 1998). However, they fail to consider related aspects of the transplantation experience which may be responsible for their findings. This restricted method has resulted in the consideration of recipients as a homogenous group. This deprives the literature not only of a more inclusive, overall understanding of the experiences of recipients, but the inaccurate representation of the individual experience.

A number of studies provided limited information as to methods used (e.g. Auer *et al.*, 1990; House, 1987). Clear inclusion and exclusion criteria were often neglected (e.g. Tanriverdi *et al.*, 2004) and conditions of testing were absent (e.g. Baines *et al.*, 2002). This is relevant when researching end stage renal failure populations, as uraemic encephalopathy can be present (Evers *et al.*, 1998), resulting in loss of memory, loss of cognitive ability and impaired concentration. These may therefore be affected by the conditions in which testing takes place.

Difficulty arises when comparing findings in this review due to the variety of measures used, often without description or justification. Over sixty different measures

were included within this review, over half of which were presented without information regarding reliability or validity (e.g. Hagberg, 1974; Reynolds *et al.*, 1993). Some studies used questionnaires designed by the authors for the purpose of the study (e.g. Hellgren *et al.*, 1994; Porter & Stone, 1995; Robello *et al.*, 2003). However, it was not stated whether these had been tested for reliability and validity, and they were not included within the publications for the reader to evaluate. The findings are therefore questionable.

There is also great disparity in the number of participants included in the studies. The average number of participants is 193, ranging from 1 (Adler, 1972) to 15,625 (Coresch *et al.*, 2003). The use of small sample sizes in some studies may limit the generalisability of the findings. For example, Pucheu *et al.* (2004) found that professional status and education were not predictive of quality of life in those with end stage renal failure. However, this was one of the smaller studies in the review (n=47), and it may therefore have been difficult to detect differences, although insufficient data were reported to enable effect size calculation. Small sample sizes may compound difficulties of the common selection of participants who have received dialysis or a transplant some time ago. A larger sample size may provide representation of a broader range of participants who have received treatment over varying time periods, such as Burton *et al.* (1998). This paper included 412 participants who had received treatment over varying time periods in order to examine the role of support in influencing the outcome of end stage renal failure. However, due to a lack of power analyses, this study may have exceeded the requirements for statistical power, therefore resulting in unnecessary research and the identification of trivially small effects (Cohen, 1990).

Only two studies within this review reported power analysis (Nui & Li, 2005; Tsay *et al.*, 2002) and none of the studies reported on their analysis of missing data. Also, in terms of demographic information, very little (e.g. Auer *et al.*, 1990; House, 1997), or none (e.g. Devins *et al.*, 1982; Steele *et al.*, 1996) was provided. This makes comparisons difficult. These issues present difficulties when establishing research quality.

No research to date appears to have accounted for the relatively older average age of renal replacement therapy patients, when compared to research of other illness populations such as breast cancer (e.g. Carver *et al.*, 1993). Studies tend to group participants by employment status as an alternative. For example, Craven *et al.* (1987) included students with retired participants, failing to account for the benefits of role identity, activity levels and the social aspects of student life.

The majority of research to date has been conducted in the USA (e.g. Benedetti *et al.*, 1994; Kimmel *et al.*, 2001; Rocco *et al.*, 1997), where significant differences in the provision of treatment exist. This is relevant as compulsory health insurance can determine the type of treatment received, creating a different context of system when compared to the National Health Service in the UK. This has been acknowledged by a few recent studies (e.g. Hicks *et al.*, 2004; Weisbord *et al.*, 2005), but the impact of American health systems has been neglected in previous American literature (e.g. Dubovsky & Penn, 1980; Short & Wilson, 1969; White *et al.*, 1990).

Within this review, only Weisbord *et al.* (2005) considered ethnicity. No differences in symptom severity or burden of kidney disease by ethnicity were found. However, the study was too small to detect significant differences in outcome by ethnicity with only 162 participants. Insufficient information was provided in order for the effect size to be determined. Ethnicity and cultural differences are severely neglected within the field, and future research would benefit from its address.

Much of the reviewed literature has noted the benefits of transplantation (e.g. Evans *et al.*, 1985; Merkus *et al.*, 1999). There has, however, been little examination of the consequences of failed transplants. Of the literature within this review, Simmons and Abress (1990) found that individuals with failed transplants had poorer quality of life than both those with functioning transplants and those on dialysis who had never had a transplant. Devins *et al.* (1982) found no differences in outcomes between dialysis and post-transplant recipients, however, failing to report on failed transplantation within the dialysis group. Weisbord *et al.* (2005) found there was no difference in symptom burden or illness severity by transplant status. These findings were based on a comparison of median scores rather than assessment of differences across the whole population. Additional valid and reliable research into the consequences of failed transplants is necessary for understanding the psychological impact of living-related renal transplantation.

There is a lack of qualitative research within the reviewed literature with only nine papers adopting the methodology (e.g. House, 1987; Martin-McDonald, 2003; Sanner,

2003). A qualitative approach can be useful in exploring individuals' accounts from their own perspectives, enhancing understanding of an experience.

3.2 Future Research

Future research should aim to resolve some of the aforementioned methodological criticisms such as the range of sample sizes, lack of power analyses, quality of report writing, use of measures, inclusion of individual differences such as age and ethnicity.

In terms of identified methodological failings, the use of large sample sizes could allow a broader range of participants of a variety of ages, who have been receiving treatment for a range of time periods. The use of power analyses could ensure that no small effects have been identified due to an excessively large sample, or that important effects have been overlooked due to a small sample (Cohen, 1990).

Enhanced methodological reporting such as additional reporting of procedure and analysis, including clarification of the analysis of missing data, would enable the quality of studies to be more reliably established. It could also allow the replication of studies in order to assess their validity.

The administration of questionnaires which are proven to be reliable and valid, rather than author questionnaires which have not previously been administered (i.e. Hellgren *et al.*, 1994; Porter & Stone, 1995; Robello *et al.*, 2003), would enhance both the

validity and reliability of the study. This could subsequently broaden the generalisability of findings (Cronbach *et al.*, 1972).

The lack of research exploring any influence of cultural and ethnic diversities may be due to a lack of validated measures in foreign languages. This has resulted in the current body of literature being unrepresentative of the experiences of renal populations as a whole. Further research should consider how to include a diverse range of participants perhaps through the translation and validation of questionnaires or via qualitative research methods.

The increased use of qualitative methods would also allow for the exploration of the individual experience, and reduce identified tendencies to fragment elements of the experience. The inductive nature of qualitative research would provide opportunity to reveal elements of experience which may not be addressed within the existing literature, such as the consequences of a failed transplant.

The examination of recipients' experiences from their own perspectives is crucial for providing comprehensive understanding and accurate representations of their experiences with living-related renal transplantation.

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Section B

Research Report (Option 1)

Recipients' Experiences of Living-Related Renal Transplantation

Word count (excluding references): 17282

Abstract: Recipients' Experiences of Living-Related Renal Transplantation

Objectives. The current study aimed to explore the experiences of living-related renal transplant recipients.

Design. An interview design using a self-selecting sample was adopted.

Method. Semi-structured interviews were undertaken with eight individuals who had each received a kidney from a living-related donor within the last nine years, and were currently outpatients at an East Midlands acute hospital following transplant. Transcribed interviews were analysed using Interpretative Phenomenological Analysis (IPA).

Results. A total of twenty sub themes emerged, which reflected the participants' experiences. From this, five super-ordinate themes were elicited and organised to form a narrative account and models to reflect the interconnectedness of participants' experiences. Super-ordinate themes identified were: story of illness, kidney as a gift, uncertainty about the future, coping mechanisms and liberty.

Conclusion. Themes generated an insight for health professionals working in the field of renal medicine who are involved in the preparation and recovery of living-related renal recipients. Further research is required to examine the impact of transplantation on family members, and to assess the progression of psychological processes over time. It is also important that health professionals facilitate discussion of recipients' feelings regarding transplant, and do not underestimate the psychological impact of the procedure. Clinical practice should consider inclusion of pre-operative information and education on how to convey information by health professionals and systemic working between health professionals and post-transplant care facilities.

Word count: 225

1.0 Introduction to the current study

The present study aims to understand the experiences of recipients with end stage renal failure who have received a kidney from a living-related donor. This section provides an introduction to the study, beginning with a discussion of the psychological distress which can result from kidney disease. This is followed by an explanation of the origins of living-related renal transplantation and the enhanced outcomes of the procedure, compared to cadaveric transplantation. Literature regarding the psychological consequences of living-related transplantation is presented, followed by a critique of this research. The section ends with a rationale for the current study which then commences in section 2.0, Method.

1.1 Psychological distress from kidney disease

Chronic kidney disease is a long-term condition, potentiated by a number of pathological processes which ultimately involve damage or abnormality in both kidneys and loss of kidney function (Department of Health, 2005). The National Service Framework for Renal Services (Department of Health, 2005) reports the prevalence of diagnosed chronic kidney disease to be 5,554 per million population (John *et al.*, 2004). Approximately 5% of those with kidney disease will develop end stage renal failure (Coresch *et al.*, 2003). Since the kidneys' primary role is one of blood purification and homeostasis, kidney disease can be fatal without dialysis or a kidney transplant (Department of Health, 2005).

Psychological distress has been found to be highly prevalent for patients living with chronic renal disease (Kimmel *et al.*, 1998) contributing to greater morbidity and mortality in the population (Finkelstein & Finkelstein, 2000). The threat of death, reduced life expectancy, lessening physical strength, and an often intrusive medical regime (Will & Johnson, 1994) appears to contribute to psychological distress.

Of psychological morbidity, most prevalent and researched has been depression (Kimmel, 2001). It has been associated with the multiple losses that accompany the disease such as loss of role within the family and social settings, loss of mobility, renal function, sexual function and cognitive abilities (Kimmel *et al.*, 1993). The gruelling regime of dialysis appears to exacerbate psychological distress with negative impact on quality of life (Molzahn, 1991). It has also been associated with increased anxiety (Martin-McDonald, 2003). Given the suggestion that stressors associated with disease and treatment may increase vulnerability to psychological distress (Kimmel, 2002), kidney transplantation may act not only to dramatically improve physical health but may reduce potential stressors (Gould & Wainwright, 1997).

1.2 Enhanced outcomes with living-related renal transplantation

Recent years have seen an increase both in patients waiting for renal transplant and a corresponding drop in the number of cadaveric donor transplants (United Kingdom Transplant Support Service Authority (UKTSSA), 1998). There are a number of reasons for the shortage of kidneys for donation. Seat belt legislation,

drink-driving regulations, safety initiatives and improved car design, have all contributed to a fall in the number of road traffic fatalities (UKTSSA, 1998). These are all major sources of donated organs. This has been paralleled by a reduction in the number of deaths from intracranial haemorrhage, another principal source of donated organs (Jakobsen, 1995).

The shortage of kidneys from cadaveric donors, and a lack of alternative sources, has created increased interest in use of living-related donors (Spital, 1993). Indeed, the number of living-donor renal transplants being performed is increasing, with a rise of 30% between 1997 (121 transplants) and 1998 (181 transplants) (UKTSSA, 1998). Rates of survival for recipients are higher than for cadaveric kidney transplant, and confer significantly reduced risks to the donor (Betram *et al.*, 1995). The five-year renal functioning rate for living-related donor transplants is 13% higher than for cadaveric kidneys (Gjertson & Cecka, 2000) and post-operative complications occur in about 8% of cases (Sandmann, 2003). The mortality rate lies between 0 and 0.03% in living-related transplants (Peters *et al.*, 2002) compared to the mortality rate of cadaveric recipients between 0.02 and 0.44% (Schnuelle *et al.*, 1998).

The majority of living-related renal recipients (80%) report enhanced quality of life in physical, emotional and social domains after transplantation (Simmons, 1983). Psychological well-being, including indices of happiness and anxiety, quality of self-image, satisfaction with marital and sexual relationships, and vocational rehabilitation, show dramatic improvement one year post-transplant. This is in comparison to pre-transplant, and when compared to the general population

(Simmons *et al.*, 1977). Twice as many well functioning donor-recipient relationships have been reported after a positive outcome of living-related transplantation as compared to a negative outcome (Simmons, 1981).

1.3 Consequences of living-related renal transplantation

The current study aims to understand the experiences of recipients with end stage renal failure who have received a kidney from a living-related donor. Consideration of existing literature, which examines the psychological consequences of the procedure, can inform understanding of the experience of transplantation and is therefore relevant to the current study. The literature tends to focus on circumscribed aspects of the procedure such as depression (Akman *et al.*, 2004; Heck *et al.*, 2004), anxiety (Baines *et al.*, 2002; Tanriverdi *et al.*, 2004) and stress (Frey, 1990; Hayward *et al.*, 1989). The format of this section therefore reflects this tendency. It begins with the presentation of literature regarding depression, followed by research concerning anxiety, stress and difficulties integrating the kidney. This is followed by consideration of the methodological failings of the literature.

1.3.1 Depression as a consequence of living-related renal transplantation

Depression is considered usual in adjustment to renal transplant (Kimmel *et al.*, 1998). Suggested causes of depression have been loss of role within the family, loss of physical abilities, cognitive abilities and sexual function (Rocha *et al.*, 2001). In a Turkish study, Tanriverdi *et al.* (2004) found that feelings of guilt, worthlessness, hopelessness and helplessness are common symptoms of depression in living-

related renal recipients. Symptoms are associated with poorer physical functioning, vitality, mental health, and greater physical limitations compared to non-depressed controls. Low self-esteem and non-compliance with therapy can result from depression, affecting kidney and recipient survival (Frazier *et al.*, 1994).

Akman *et al.* (2004) examined the relationships between depression and the psychosocial parameters age, gender and marital status, and level of kidney functioning. Severity of depression was found to be lower among married patients with a living partner, suggesting the sharing of problems acts to initiate mood decrease. Transplant failure was related to more severe depression when compared to recipients with a graft of longer functional duration. No relationships between age, gender and depression were identified. This may be the result of the majority of respondents being young and subsequently having returned to an active lifestyle following transplantation. A small number of female participants in the study was insufficient to assess their reaction to transplantation and to generalise the findings to the young, female population.

1.3.2 Anxiety as a consequence of living-related renal transplantation

Anxiety has been identified as a consequence of living-related renal transplantation (Baines *et al.*, 2002; Tanriverdi *et al.*, 2004). In a recent study, Baines *et al.* (2002) identified concern for the survival of the organ to be a primary source of anxiety. Worry regarding the loss of the kidney and uncertainty of life remaining was found to provoke time searching for certainty and close attendance to bodily changes. As a consequence, social and developmental paralysis emerged (Baines *et al.*, 2002).

Cognitive models of anxiety may provide explanation by emphasising the sensitivity of cues predictive of danger (Clark *et al.*, 1988). Those who have received a transplant may have a heightened awareness of their body due to increased attention paid due to transplantation. Recipients may be highly sensitive to bodily changes which could then be misinterpreted in a threatening manner i.e. thoughts regarding the loss of the kidney. This in turn may exacerbate anxiety, producing symptoms to which the recipient reacts with more anxiety.

Concern for the health of the living-related donor has also been found to be a significant source of anxiety to recipients (Dubovsky & Penn, 1980). Sanner (2003) suggests that this is related to recipients' beliefs that the donor is more vulnerable to disease following the loss of the kidney, or may have been harmed during the procedure. Anxiety of this nature has been associated with feelings of guilt at receiving the donor's kidney (Sanner, 2003).

The Health Belief Model was initially developed to predict preventative health behaviours (Becker, 1974). However, it has also been used to predict the behaviour of chronically ill and recovering patients and may be useful in explaining anxiety regarding the donor. According to the model, the perceived threat of the illness is a function of the individual's perception of the seriousness of the health problem, his/her perceived susceptibility to it and cues to action. Therefore, perceived threats and subsequent anxiety regarding the loss of the kidney may be maintained by beliefs that the kidney is not robust. Perceptions of the donor as being vulnerable to illness, or regarded as physically weak due to the presence of a single kidney, may result in anxiety regarding the donor's health. A criticism of the model is its

inability to measure components such as perceived susceptibility or seriousness in a standardised, reliable way.

1.3.3 Stress as a consequence of living-related renal transplantation

A potential consequence of transplantation is stress. This is defined by Lazarus and Folkman (1984) as the relationship between an individual and the environment which is perceived as exceeding their resources. White *et al.* (1990) examined the association between stress and coping in living-related renal recipients. They identified renal function and general state of health as primary stressors. Those experiencing the greatest stress reported lowest quality of life, and used more coping strategies. In a similar study, Hayward *et al.* (1989) identified the most common stressor as the fear of rejection of the kidney, followed by the possibility of infection, uncertainty of the future and the side effects of medication. The first six months post-transplant have been considered to be the most stressful due to high risk of infection, frequent hospital visits and adjustments to medication and side effects (Suthanthiran & Strom, 1994).

Side effects of anti-rejection medication following transplant such as weight gain, excessive hair growth, warts, ulcers and bruising have been found to create body image concerns for recipients (Fallon *et al.*, 1997). Altered body image has been associated with increased anxiety and distress (Fallon *et al.*, 1997), linked to the recipient's inability to adapt to their new self-image, and integrate the new kidney into this image (Schover, 1991).

1.3.4 Difficulties integrating the kidney into the self as a consequence of living-related renal transplantation

The integration of the kidney has been described as a complex process (Muslin 1971). In a series of case studies, Basch (1973) argued that recipients develop attitudes towards the transplanted kidney, affecting the way in which the organ is accepted and integrated. The integration of the kidney is considered to occur within a spectrum, whereby some recipients appear to immediately incorporate the organ, and others may continue to view it as a foreign object (Basch, 1973). Integration has been found to be problematic in males who receive a kidney from a female donor (Muslin, 1971). High incidences of rejection in these cases have been attributed to interpersonal issues arising from cross gender transplants which impede the integration of the kidney. For example, the belief that the presence of a female organ will reduce sexual functioning has been identified (Basch, 1973). Women who have received a kidney from male donor have reported to perceive their kidney as being stronger than a female's (Sanner, 2003). Sanner (2003) attributes these beliefs to the strength of gender stereotypes.

1.4 Methodological failings of the literature

A number of methodological failings exist in the presented literature. The main problems include: fragmentation of the experience of living-related renal transplantation, over reliance on quantitative methods, over interpretation of single case studies and a lack of qualitative research.

Existing studies which have explored the consequences of living-related renal transplantation have tended to focus on fragmented aspects of transplantation such as depression (Akman *et al.*, 2004), anxiety (Baines *et al.*, 2002) or stress (Frey, 1990). The inclination to identify specific elements of the experience of transplantation has resulted in the consideration of recipients as a homogenous group. This deprives the literature not only of a more inclusive and overall understanding of recipients' experiences, but also of an accurate representation of the individual experience.

The predominant use of quantitative studies designed to test specific hypotheses, may have resulted in the neglect of other presenting consequences of transplantation. Fragmented aspects of transplantation such as depression and anxiety are therefore frequently repeated within the literature. This has resulted in a lack of consideration of any possible alternative consequences. Although providing a framework which values objectivity, quantification and measurement, quantitative approaches are predominantly psychometric. However, they have been critiqued for simplifying the complex experience of living-related renal transplantation (Lamiell, 1995).

The presented quantitative literature used a variety of methods of data collection, often without adequate justification or description. Methods included the use of self-reports of mood (i.e. Frazier *et al.*, 1994). Data collected by such means tends to be more subjective and idiosyncratic (Barker *et al.*, 2002). Participants may not always be truthful, preventing honest and reliable responses (Barker *et al.*, 2002).

Translated questionnaires were also used for data collection. The Beck Depression

Inventory (Beck *et al.*, 1961) was translated into Turkish for a study by Tanriverdi *et al.* (2004). Although it has been shown to be a reliable and valid instrument in America, the reliability and validity of its translation for this study is questionable. Social conventions and cultural assumptions can affect test items if they are not standardised within the relevant population (Hayes, 1994), resulting in skewed data.

Single case design methodology was used to examine the integration of the kidney into the self (Basch, 1973; Muslin, 1971). These studies are overly interpretative and not disprovable. Speculation rather than empirical evidence based upon the examination of single cases may result in limitations when generalising findings.

There is a distinct lack of qualitative research examining the psychological consequences or experiences of living-related renal transplantation. That which is presented is questionable (Baines *et al.*, 2002). Data was analysed by searching for pre-conceived themes. This is inevitably partial and may have resulted in the neglect of potential alternatives. The lack of reliable and valid research designed to explore individual accounts and provide in-depth analyses of experiences is a failing which requires addressing.

1.5 Current study

The current study aimed to examine recipients' experiences of living-related renal transplantation. An inductive, qualitative methodology to allow for the exploration of individuals' experiences from their own perspective was thus adopted. This was anticipated to achieve greater understanding and accurate representation of the

experience of living-related renal transplantation to add to augment the existing body of research. It aimed to address some of the aforementioned methodological issues, such as the lack of qualitative research, over reliance on quantitative methods and fragmentation of the experience of living-related transplantation. It also aimed to explore aspects of living-related transplantation other than those repeatedly identified.

2.0 Method

This section describes the study design, together with a rationale for using Interpretative Phenomenological Analysis (IPA) as a method for interpreting qualitative data. Personal responses to the analysis, issues of rigour and validity, and the question of reflexivity, are addressed in more detail in Section C.

2.1 Design

The previous section noted that psychological factors have been partially identified and examined in the existing research (e.g. Akman *et al.*, 2004; Tanriverdi *et al.*, 2004; White *et al.*, 1990) among recipients of living-related kidneys. However a comprehensive approach founded in recipients' own experiences is lacking. Thus a qualitative methodology was employed in order to explore how individuals 'perceive events within the context in which they occur' (Giorgi & Giorgi, 2003, p.26).

Following the decision to employ a qualitative methodology, an interview design using a self-selecting sample was adopted. An interview design provides a relatively unthreatening environment in which experiences can be discussed. It also allows for the use of a semi-structured interview schedule to encourage the emergence of relevant topics (Smith, 1995). A self-selecting sample, that is 'a sample selected for study on the basis of their own action in arriving at the sample point' (Coolican, 1994, p. 45) allowed participants to volunteer to take part in the study without any perceived pressure to do so (Silvermann, 2000).

2.2 Interpretative Phenomenological Analysis as a qualitative method

Interpretative Phenomenological Analysis (IPA) was selected as the method of analysis for the interview transcripts. A principal assumption of IPA is that verbal statements can meaningfully reflect the internal world and underlying assumptions of the individual. Semi-structured interviews are used to provide the researcher with data. IPA then provides a structured analytic framework in which the personal meanings in individuals' accounts can be organised and made sense of. Engaging with the data enables interpretations to be produced for each participant, followed by links that are formed across participants.

Smith (2003) maintains that the process of interpretation involves a filtering of participants' accounts through the researcher's own perceptions and biases. Therefore, although IPA provides a structured analytic framework with which to make sense of personal meanings, this is with the acknowledgement that the research exercise is seen as a dynamic process in which the researcher assumes an active role. The researcher begins with a detailed examination of one case until a degree of gestalt has been achieved. A case by case analysis then takes place of further transcripts. The aim is to produce an interpretative account of the perceptions and understanding of the participants in the study, which is grounded in what they have said.

The recipient's perspective of acquiring a kidney from a living-related donor is an area which has lacked global empirical analysis. Of the research that exists, the focus has been on specific psychological factors which may have occurred on

receiving an organ (Tanriverdi *et al.*, 2004), or is presented as comparisons of psychological well-being between donors and recipients. The majority of research addressing live donor transplantation focuses on the psychological state and processes of the donor, rather than on the recipient. The issues that may arise for recipients have not been explored adequately due to the use of focused, primarily, quantitative methods. It is assumed that the experience of receiving a kidney from a living-related donor will be reflected within participants' narrative accounts.

As the primary aim of the study was to understand what it is like to receive a kidney from a living-related donor, Interpretative Phenomenological Analysis (IPA, Smith *et al.*, 1999) appeared an apt methodology. As a method, IPA 'has a theoretical commitment to the person as a cognitive, linguistic, affective and physical being and assumes a chain of connection between their thinking and emotional state' (Smith, 2003, p.52). IPA was chosen due to the emphasis it places on exploring participants' personal perspective on the topic under investigation. Furthermore, IPA is a distinctively psychological approach centred on the psychosocial world of the individual (Smith, 2004).

2.3 Participants

Eight participants, whose identities were all anonymised with pseudonyms, were recruited from the East Midlands Hospital in which the study took place. Only the researcher had access to information linking participant details to pseudonyms. Table 1 below shows the demographic information collected. 4 male and 4 female participants with an age range of 18 to 73 years were recruited. They fulfilled the

criteria of being 18 years of age or over, and having received a kidney from a living-related donor over twelve months ago. Two of the recipients had received a kidney from a spouse. The renal unit in which the research took place, classifies spousal relationships as living-related. A recent British Medical Journal publication also considers the spousal relationship to be living-related, because although not genetically similar, the declaration of marriage dictates that legally, they are related (Al-Khader, 2005). The emotional attachment and investment within the relationship is considered comparable to genetically related family members, and for the purpose of this research, was considered to enrich the data.

Table 1: Background Information of Participants

Code	Gender	Age	Ethnicity	Years since transplant	Living-related donor
Participant A	Male	43	White British	9	Mother
Participant B	Female	18	White British	1	Mother
Participant C	Male	73	White British	5	Son
Participant D	Female	24	White British	5	Mother
Participant E	Male	52	White British	3	Wife
Participant F	Male	46	White British	4	Sister
Participant G	Female	53	White Irish	6	Brother
Participant H	Female	48	White British	4	Husband

2.4 Procedure

2.4.1 Ethical approval

Ethical Approval was obtained from the relevant local research and ethics committee in February 2006 (Appendix C).

2.4.2 Recruitment of participants

The researcher became aware that an East Midlands Hospital operates a renal unit considered to be successful and pioneering with regard to transplantation. The researcher contacted the head of the renal unit, a professor of surgery, to explain the nature and purpose of the research. The professor provided the researcher with contact details of the live donor transplant co-ordinator, who was met regularly in order to send potential participants a letter of invitation from professor of surgery (Appendix D) and a participant information sheet (Appendix E). Potential participants were selected for invitation according to the study criteria and due to an approaching annual medical review within the outpatients' clinic. Restrictions following ethical consideration prohibited the researcher from accessing patient information until an opt-in slip from the participant information sheet, stating interest in taking part in the research, had been returned. Participants were given three weeks to return the opt-in slip to the researcher's University base, in the stamped addressed envelope provided.

Eight participants took part in the study. They were selected as they returned the opt-in slips. No further recipients expressed an interest in being involved. The denominators were that they had all received a kidney from a living-related donor over twelve months ago, had been invited to take part in the study and had returned the opt-in slip.

Upon receipt of the opt-in slip, the eight potential participants who had returned opt-in slips were contacted via telephone to arrange a convenient time to discuss the study. The researcher met the eight participants at their outpatient review appointments and the study was discussed with close reference to the participant information sheet. During this time, potential participants were encouraged to raise any questions or queries with regards to the research. It was emphasised that meeting to discuss the research did not imply agreement to take part, and that a decision not to be involved would have no impact on the care of the individual or their donor. Potential participants were offered as much time as required to consider participation in the research. All eight participants agreed to participate in the study, and informed consent (Appendix F) was gained in accordance with the researcher's training (Appendix G). Participants were reminded that it was possible to withdraw from the study at any time without providing a reason. Interviews took place on the day of annual review in a room within the outpatients department where the reviews were held.

2.4.3 Data Collection

2.4.3.1 Designing the interview schedule

Qualitative researchers advocate the use of semi-structured interview, consisting of open-ended questions to encourage flexibility within the data gathering process (Smith, 2003). A semi-structured interview schedule (Appendix H) was constructed using the guidelines described by Smith (2003). The schedule was informed by a set of predetermined questions and by a review of the literature on the topic.

The aim of the interview schedule was to facilitate discussion of the research question, allowing participants to do so from their own perspective and with their own emphasis. The structure of the interview schedule involved an opening question to enable participants to feel at ease, and introduce and talk about themselves. This also served to establish rapport, as considered by Smith (1995). The interview was normally split into five sections. The first section of an introductory question enabled participants opportunity to talk about the history of their kidney problem, from when it began until the transplant took place. They were then asked about how the living-related transplant came about and any physical effects of the procedure. The third section asked participants to consider their identity and any effects the transplant may have had on the way they view themselves, or are viewed by others. The fourth part moved into talking about their relationship with the donor both pre and post transplant. Fifth, psychological processes including the experience of any emotional difficulties and changes in

mood were addressed. This section ended with a consideration of the positive aspects of the transplant in terms of health and the future.

Smith (2003) suggests that the use of a semi-structured interview schedule is a flexible and responsive way to collect data in that it facilitates rapport and empathy. It allows greater flexibility of coverage, produces richer data, and enables the researcher to explore areas that may be of concern to participants but which the researcher had not considered. Although semi-structured, the interview schedule was suggestive not prescriptive, and was used as a guide. Smith (1995) suggests that the ordering of questions is less important. During the course of interviews, this allowed the researcher to explore specific areas more deeply and to follow the priorities and concerns of the interviewee. The interviews were viewed as interactions with each participant, which further enabled the researcher to enter each individual's social and psychological world.

2.4.3.2 Interview procedure

Interviews took place in the outpatient clinic in which their annual review appointment was held. The researcher read through the participant information sheet (Appendix E) to ensure participants understood the aims of the research, the limits of confidentiality and anonymity. Opportunity was allowed for questions to be answered. The participant then signed the consent form (Appendix F) and the interview commenced. Interview duration ran up to 60 minutes and each interview was recorded on audiotape. At the end of the interview, the audio tape recorder was turned off and participants were invited to comment on how they had found the

process. The researcher made a note of these comments and made observations about the process in a reflexive diary (Figure 2).

Figure 2: Extract from reflexive diary

Second interview done – a young girl who was very robust and coped very well with the transplant. She seemed keen to talk about the transplant in terms of procedure, and had some difficulty thinking psychologically about it. I tried to help her, but felt I was putting words in her mouth. I need to think about how I can encourage participants to think more psychologically, though perhaps the content and meaning rather than exactly what it said matters more. So far they do seem to be used to talking about the transplant in a very matter of fact, medical way. I wonder if this is a reflection of how the transplant might mainly be discussed with them in practical, non-feeling terms, and shows the lack of psychological input or support, or maybe it's a way of coping.

The audio taped interviews were transcribed by a secretary using the guidelines recommended by Burman (1994). The researcher then listened to the tapes whilst following the transcripts and filled in any missing words or phrases. Identifying details were removed and kept in a separate location to the transcripts.

2.4.4 Data analysis

Analysis of the individual transcripts was undertaken in line with the interpretative phenomenological analysis approach as described in Smith *et al.* (1999). The idiographic approach starts with specific examples before moving up to more general themes (Smith, 2003). The analytic process procedure followed a number of steps and was iterative, in that each level of the analysis informed the understanding of other levels.

Stage One: Pre-transcription analysis

The researcher's initial thoughts and reflections following each interview were recorded in a reflective diary. Notes made typically incorporated the researcher's feelings about the interview, ideas for subsequent interviews and comments on what had been said.

The reflective diary was used throughout the analytic process. The development of themes and connections between themes was aided by the use of memo writing within the diary. Notes were kept on thoughts and interpretation of the data, which were then cross referenced with themes emerging from the data.

Stage Two: Micro level analysis

Smith *et al.* (1999) advocate an idiographic approach where the researcher engages in close textual analysis of one transcript and looks at this before incorporating others (Smith, 2003). The process is iterative whereby interpretations are revised and reviewed upon further reading of the transcript. Transcripts were read several times until the account was familiar. Preliminary ideas, thoughts and reflections were noted on the left hand side of the margin. The aim was to capture the summaries of the content and ideas and to offer tentative ideas about the underlying meaning of what was being said. Emerging themes, associations and connections were documented in the right hand side of the margin. An example of micro-level analysis is provided in Appendix I.

Stage Three: Macro level analysis

At this stage, the researcher listed emerging themes and looked for connections between them. These first level themes (sub-ordinate themes) were studied, revised and organised to form consistent and meaningful statements. Themes that occurred more than once within the text, or which link with each other are condensed into over arching super-ordinate themes. Preliminary diagrams of the super-ordinate and sub-ordinate themes were then drawn. This stage of analysis involves close interaction between researcher and text as attempts are made to understand what the participant is saying, and as part of the process drawing on the researcher's own interpretative resources (Smith *et al.*, 1999).

The development of themes and connections between themes was aided by the use of memo writing within the reflective diary. Notes were kept on thoughts and interpretation of the data, which were then cross referenced with themes emerging from the data.

A master theme list was developed following the three stages of analysis performed with participant A's transcript. Remaining transcripts were analysed in the same manner, however, the master theme list was referred to in order to identify more instances of the themes previously identified in participant A's transcript. New themes were also identified and were tested against earlier transcripts, making the process cyclical. The master list from participant A's transcript was used to inform analysis of the other transcripts. By remaining aware of themes which had arisen, it was possible to identify what was new and different in the subsequent transcripts,

whilst finding responses which further articulated existing themes. A final set of master, or super-ordinate themes evident within several of the individual transcripts, was completed. Themes allowed for description of experiences that are shared between individual members of the sample group. Master theme lists are provided in Appendix J, in order to illustrate its progression.

A figure of the super-ordinate themes illustrates the experiences of receiving a kidney from a living-related donor, and is presented in the next section.

3.0 Analysis

3.1 Use of excerpts

Excerpts from the transcripts were used to aid clarity and support the process of analysis. All data excerpts appear *italicised* to distinguish them from the text.

Excerpts detail the pseudonym of the participant, provided to protect anonymity, and a line number that corresponds with the start of the excerpt in the transcript.

The following conventions were used in relation to the excerpts: '(pause)' indicates a pause in speech, and a series of three dots '...' represents the omission of text. Where relevant, non-verbal information was included to contextualise the excerpt such as (laugh). Any information which could threaten anonymity such as names of people or places, was excluded from the transcripts and recorded for example as (husband's name).

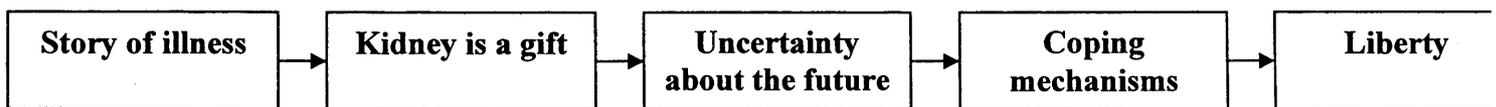
3.2 Overview of themes

A total of eighteen subordinate themes emerged, which reflected the participants' experiences. A large number of subordinate-themes created a challenge in the extracting of super-ordinate themes. Five super-ordinate themes were elicited by collating and amalgamating groups of sub-themes that were common across transcripts. The super-ordinate themes were organised to form a narrative account, drawing upon the experiences of individuals to illustrate the features of the shared

sub- and super-ordinate themes. Excerpts from the data illustrate and ground the narrative in participant accounts.

Figure 3 depicts the shape of the analysis, reflecting the connections of participants' experiences. It demonstrates the linear process of receiving a kidney from a living-related donor, illustrating the experiences from illness through to recovery.

Figure 3: Diagram of super-ordinate themes



The super-ordinate themes are presented in a linear diagram to encapsulate the succession of processes undergone during the experience of receiving a kidney from a living-related donor. The diagram should not be regarded as static, or rigid in structure, however, but as fluid in nature, where super-ordinate themes may recur outside of the order imposed. Aspects of the diagram will now be discussed in more depth.

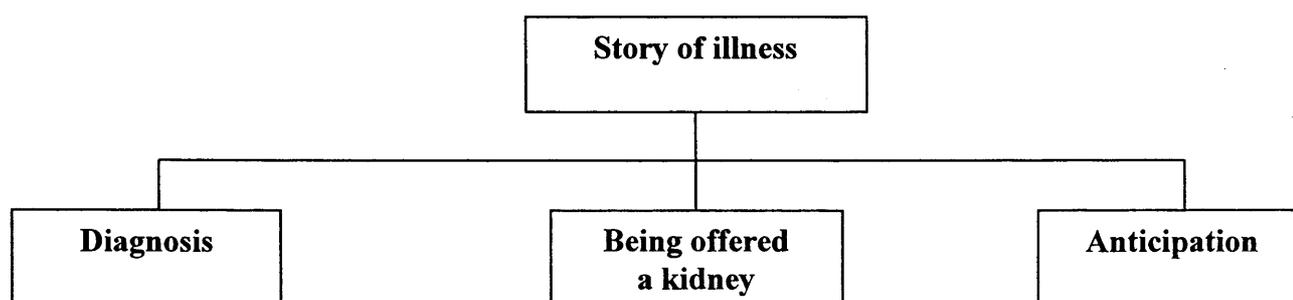
3.3 Super-ordinate theme 1: Story of Illness

'Story of Illness' is the starting point of the analysis, encompassing the experiences of participants prior to transplantation. The theme is primarily phenomenological, outlining participants' journey through illness to transplant. The theme is illustrative of how recipients make sense of their illness, and the way in

which they talk about their illness, in a chronological, expressive manner. Within these stories, there are features shared by all recipients. The subordinate themes represent recipients' experiences from kidney problem to transplantation, illustrating the range of feelings experienced throughout the period. 'Story of illness' terminates at the point of transplantation, according to participant accounts in which recipients consider themselves to be healthy rather than ill individuals following transplant: Edward: *'The next day (following transplantation) um, I was feeling on top of the world'* (90), John: *'The transplant, it works very quickly...within two or three days I felt a lot better'* (257).

Figure 4 depicts the three subordinate themes that constitute 'story of illness'. Each theme will now be presented in more detail.

Figure 4: Story of Illness - diagram of subordinate themes



3.3.1 Story of illness subordinate theme 1: Diagnosis

The subordinate theme diagnosis reflects the experience of learning about a kidney problem and the need for a transplant concurrently. Many participant accounts

consider the two, simultaneously having being diagnosed with kidney failure and being informed of the need for transplant within a short time period. Subsequent to diagnosis, some participants had been notified that a transplant would be required in the future. They were not provided with an estimated time period for when transplantation would be necessary.

These excerpts illustrate the experiences of those who were diagnosed with kidney failure without any previous awareness of a kidney problem. They illustrate the experience of being diagnosed, and the reaction of shock to the news.

Kate: *'I went to the doctors and they said I would have to go to hospital and I ended up staying two weeks...the second day they told me it was a kidney problem, and put me on dialysis the third day so (short laugh) it happened quite quick really so I didn't really like realise what was happening'* (16).

Linda: *'I had a thyroid problem so I had to go to (names hospital) and they said there was a problem with my kidneys... I was afraid. I thought 'no, I'll, I'll beat it, I'll go back to work and I won't bother going'. I was afraid, but in the end, eventually, I had to get checked. My kidneys had failed. I needed to go on dialysis which was a real shock'* (11).

Some participants were informed of the need for a transplant soon after kidney failure diagnosis. These excerpts appear lacking in emotional response, reflective of the numbness and shock experienced at prognosis.

Caroline: *'The first day I was in hospital, they suggested it (the transplant) straight away' (25).*

Interviewer: *'At what point did discussion about a transplant come about?'*

Kate: *About (slight pause) it was about five days after (diagnosis)' (46).*

For others, kidney failure was a gradual process. Decline of kidneys had been diagnosed and monitored for some time, and transplant was regarded a future, rather than urgent prospect. Participants' accounts are factual in report, and less affectively nuanced. They are reflective of repeated monitoring and consideration of the inevitable transplant.

Edward: *'I started to find out about transplants 25, 26 years ago when I came in for a knee operation and they told me I would need a kidney at some time, or to go on dialysis but they told me they would monitor me over a period of time...so they, er, kept a check on me for 20 years. Each time I came every year, I was told they were going down a little more, so after 20 years they got to a position where they said I would need to go on dialysis or have a transplant' (5).*

Peter: *'I was probably in my mid-twenties and then I found out I had kidney problems so from then on I had various treatments really aimed at staving off the transplant and dialysis' (10).*

3.3.2 Story of illness subordinate theme 2: Being offered a kidney

The process of transplantation dictated that once informed of the need for transplant, potential donors needed to be identified. Participants did not approach potential living-related donors. In contrast, relatives offered to be matched. None of the participants rejected a donor's offer of a kidney. These excerpts illustrate the offer of a kidney from the donor.

Peter: *'From the moment I said 'well, y'know, the kidney function's dying' she (mother) said, 'well y'know I'm quite happy to offer one of mine' (51).*

Kate: *'My mum and dad both volunteered so they both got matched and my mum was the best match out of it' (55).*

The most appropriate candidate for donation was considered. These excerpts illustrate the basis on which relatives made the decision to donate, and capture the unquestioning response of the recipient. The decisions to accept were straightforward and founded on current and future circumstances of the donors.

These excerpts feel emphatic, decisive and non-consultative.

Steven: *'I've got two sisters and they were both compatible. One was keener than the other: one hasn't got children, the other one has. The one that hasn't got children was the keenest which I can understand...she was more keen, so that was as simple as that really' (54).*

Edward: *'My two sons both said, 'No, we are definitely going to give you one of our kidneys'...My youngest son said, 'It's gonna be me' just like that! And I said, 'Why is it going to be you?' His answer was, 'You've done so much for me in the past, it's got to be me' (29).*

Recipients appear to construe responsibility for the decision to donate solely to potential donors, seeming to attempt abdication of responsibility. They considered that the decision to donate should be made autonomously by the donor.

John: *'It's that one person (the donor) who has to make the decision, and I, I, y'know, my decision is I have to sit back and have a transplant. My wife's decision is to, to donate the kidney and that, that two very difficult, two different decisions I think' (161).*

One recipient made the decision to finally accept the long-standing offer a kidney, due to a change in her own circumstances.

Linda: *'My brother kept offering it (the kidney) to me, so when my mother died, I thought I'd better have it done' (88).*

3.3.3 Story of illness subordinate theme 3: Anticipation

Following the organisation of a living-related donor, participants experienced feelings of anticipation. For some, anticipation of the surgery was related to the prospect of ceasing dialysis.

Kate: *'I wasn't really that worried. I was more excited to like get it (the surgery) done and get over dialysis'* (85).

Steven: *'I was actually er looking forward to it (the surgery) in a way because I knew I couldn't carry on how I was'* (72).

Anticipation was expressed as anxiety regarding the operation, as participants realised the enormity of the procedure. Conflict existed between anxiety and a need for the transplant.

John: *'I did obviously have to have the transplant and I think once you get round that thought that's...quite difficult because y'know, it's a major operation...what you've got is something which in effect is life-threatening, so y'know to have a transplant is a, is a big thing'* (141).

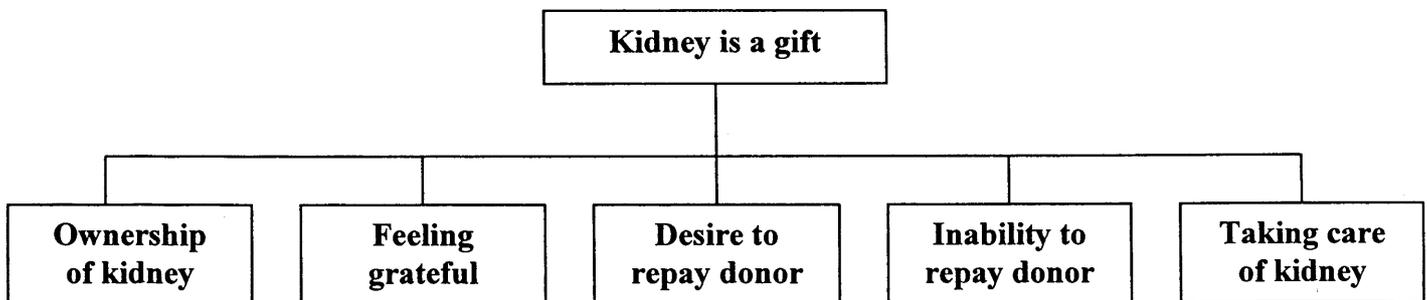
Caroline: *'I was generally scared cos I hadn't, I'd only had like grommets and sort of tooth operation when I was younger, it wasn't like big surgery... I was quite scared that I wouldn't be able to cope with the pain'* (204).

Linda: *'I was afraid, not afraid of it, I wanted to have the transplant, y'know, just afraid of coming into hospital, and er, best thing I ever did'* (96).

3.4 Super-ordinate theme 2: Kidney is a gift

The second theme describes a framework for understanding the consideration of the kidney as a gift. It reflects participants' reports, which describe the kidney as a gift: *'It's a gift'* (John, line 584), *'It's a great gift'* (Peter, line 541). The theme is weighty of the analogy of the kidney being a gift. It explores the emotions experienced upon receiving the kidney, and the perceived obligations towards both the donor and the kidney. Participants conveyed feelings with senses of desperation, long-term struggle, and lack of resolution, captured within the quotes. Figure 5 depicts the subordinate themes that constitute this theme.

Figure 5: Kidney is a gift - diagram of subordinate themes



3.4.1 Kidney is a gift subordinate theme 1: Ownership of kidney

Participants varied in their beliefs about who owned their transplanted kidney. A few were confident of the owner, due to their interpretation and meaning of being given the kidney. Statements were conveyed with a degree of conviction and certainty.

Linda: *'My kidney...since my brother gave it to me'* (434).

Kate: *'It belongs to me now'* (224).

The owner of the kidney was sometimes interchangeable, depending on the presence or absence of the donor. It also appears to be contextually driven.

Caroline: *'I say 'my kidney', but when I'm at home, I say like 'me mum's kidney''*
(433).

Edward: *'I feel now that it is my kidney but, when we refer to it, we still refer to it as 'his young kidney'*

Interviewer: *Right, right, when he's around is that?*

Edward: *Oh, ah, absolutely'* (353).

Within spousal relationships, the kidney was regarded as an amalgamation of the recipient and the donor, perhaps reflective of the synergetic, sharing nature of the married relationship.

Rose: *'I suppose because it's in me...it's both of us really'* (431).

John: *'It's sitting there, and working for me instead, it's, it's quite nice really (laughs)'* (579).

3.4.2 Kidney is a gift subordinate theme 2: Feeling grateful

All participants explicitly described feeling grateful to their donor, regardless of time period since transplantation. The use of the present tense suggests that feelings of gratitude remain despite the passage of time. The excerpts imply the necessity of gratitude, perhaps due to socially defined obligations.

John: *'I am obviously very grateful'* (596).

Caroline: *'I always put 'P.S. Thanks for the kidney''* (450).

Rose: *'I'm really grateful that he's done it'* (500).

Peter uses the past tense to describe feeling grateful. The death of his donor may have provided relief from feelings of gratitude experienced while his donor was alive.

Peter: *'I was very grateful'* (527).

3.4.3 Kidney is a gift subordinate theme 3: Desire to repay donor

Participants described a desire to repay their donor. Attempts at achieving this included thoughts of financial compensation, or showing good behaviour. The purpose of these is to reimburse the donor, relieve feelings of gratitude for the

recipient and restore imbalances within the relationship. The excerpts suggest that the natural order within their relationship with the donor has become disrupted.

Peter: *'Birthdays and Christmas...think maybe you should put something extra in there'* (553).

Caroline: *'I think, 'oh I wish, I really wish I could get mum that...if I had the money' ...I try to be good!'* (461).

Edward: *'You feel somewhat obligated to your son'* (148).

3.4.4 Kidney is a gift subordinate theme 4: Inability to repay donor

The desire to repay donors was accompanied by feelings of inadequacy at the inability to sufficiently reimburse. Presented excerpts illustrate participants' sense of helplessness to the realisation that they are unable to remunerate the donor in a manner that parallels their 'gift'.

Edward: *'I couldn't do enough for him because of what he had done for me'* (129).

Peter: *'It was a sort of hopelessness that you couldn't, y'know, because there's no way you can sort of quantify it if you like...you sort of felt in her debt all the time'* (562).

Participants commonly described the inability to repay their donor in a questioning manner, as if continuing to search for a means of successful repayment, or for reassurance from the interviewer of the impossibility of repaying in equal terms, therefore easing feelings of inadequacy. Despite questioning tone, statements also have a sense of finality suggesting participants are resigned to the unfeasibility of repaying their donor in an equivalent way.

Caroline: *'There's nothing that, I don't know, could I make it up?'* (469).

Linda: *'So what can I say? You'll never be able to open a stomach and give him a kidney'* (190).

Rose: *'I'm just very grateful, I mean, what can you do for him to make it up? I can't'* (507).

3.4.5 Kidney is a gift subordinate theme 5: Taking care of kidney

Participants describe taking care of the kidney, although their motivation for doing so differs. These excerpts suggest a sense of obligation drives the need to take care of the kidney.

Linda: *'I've got to look after it haven't I? My brother gave it to me'* (676).

Peter: *'You do have to look after it'* (119).

Taking care of the kidney is also driven by the wish to prolong the organ's life.

John: *'You have to keep yourself healthy and keep the kidney there'* (839).

Recipients describe taking care of the kidney by protecting it when its safety is potentially threatened.

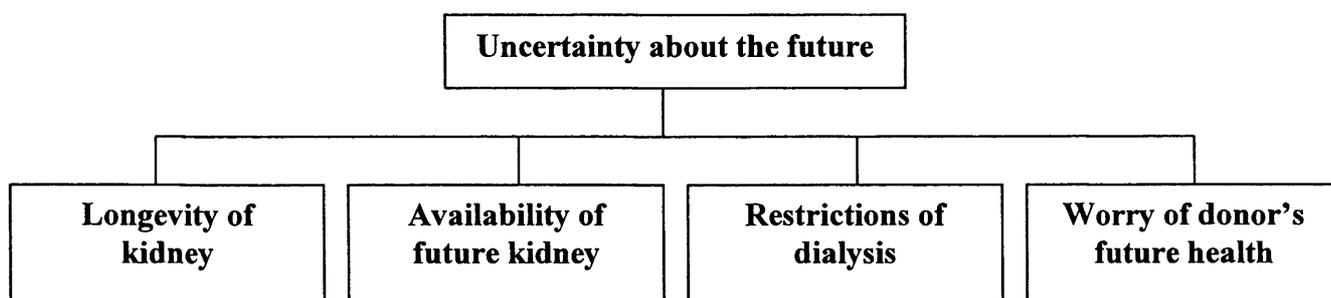
Peter: *'The kids will run up...watch if they're on to full speed on that side'* (136).

Steven: *'I'm certainly very wary when I'm sorting out the cattle...not to get too close to be kicked'* (501).

3.5 Super-ordinate theme 3: Uncertainty about the future

'Uncertainty about the future' encapsulates the current concerns of living-related kidney recipients. Following transplant, recipients commonly experience worries related to the future of the kidney on which they consider their life is dependent. Interestingly, little consideration appears to be given to any alternative potential threats to future life such as other illness. Focused attention towards the kidney has been paid since diagnosis and it is therefore understandable that the kidney becomes the sole factor considered to prolong life, and that the likelihood of its failure, and the consequences of failure, are foremost in the thoughts of participants. Figure 6 depicts the various subordinate themes that constituted uncertainty of the future.

Figure 6: Uncertainty about the future - diagram of subordinate themes



3.5.1 Uncertainty about the future subordinate theme 1: Longevity of kidney

This theme reflects participants' concern for the life span of the kidney, and reflects the unpredictability experienced. This is an ongoing phenomenon for participants following transplantation, and may continue to be present until the kidney fails.

John: *'This kidney might last another three years, it might last another thirty'* (469).

Individual beliefs regarding potential longevity of the kidney appear shaped by information conveyed by other recipients. Professional prognoses from staff were not mentioned during accounts, and appear minimised compared to information gathered from fellow recipients, perhaps considered as more reliable.

Rose: *'I've spoken to some people who've had them for years and years, hopefully I'm looking forwards towards that'* (308).

Caroline: *'When I had my transplant, there was a lady in the ward with me and she had one off her mum and she, she just came up to me and said 'don't have your hopes up, mine only lasted six years' ...just cos she said that so I thought mine would only last six years then'* (248).

For younger participants, the need for another kidney later in life, is regarded a certainty. This knowledge appears to provide participants with a degree of predictability, and a fatalistic attitude.

Kate: *'It won't last the rest of my life I know that, so basically I will have to have another transplant'* (581).

3.5.2 Uncertainty about the future subordinate theme 2: Availability of future kidney

Thoughts of the kidney's longevity often appeared to prompt participants to consider availability of a future kidney. Contemplation of which evoked an emotional response of expressions of low mood and anxiety.

Steven: *'Where that kidney would come from, er, I don't know, to be honest. Erm, you can get me all depressed now (laughs)'* (910).

Kate: *'I'm worried who I'll get one off...and will I have to go back on a waiting list?'* (581).

Consideration of a potential future donor caused a degree of uncertainty, which was explicitly expressed. Uncertainty was related to the future donor's inability to provide a kidney, and the subsequent effect of this on the participant.

Caroline: *'If my sisters couldn't give me one if it didn't match up, like three er tissue types or more, then what would I do?'* (283).

Rose: *'It does worry me a bit. I guess my son would be a match, er, or maybe my brother, but he's older so probably not'* (630).

Some participants were confident in the availability of a future kidney, commonly fathers who expected that their children could provide a kidney.

Edward: *'My eldest son still says 'that if anything happens dad, the kidney's there for you''* (173).

John: *'One of them will probably have the magic kidney as they call it, which will be a perfect match because they're an offspring of me'* (450).

3.5.3 Uncertainty about the future subordinate theme 3: Restrictions of dialysis

The contemplation of future potential options should the transplanted kidney fail initiated thoughts of second transplantation and dialysis. Dialysis, although viewed as a means of prolonging life, was regarded as restrictive when compared to the

freedom provided by a transplant. Dialysis seemed to signify a loss of independence. Consideration of returning to it evoked extreme reactions.

Linda: *'I'd rather be dead than go back on dialysis, cos it's (the transplant) that good. It's like a normal life'* (206).

Rose: *'It gave me freedom, from, from dialysis. I was getting down with that. If anything happens with the kidney. I don't want that again'* (710).

Steven: *'If I was on dialysis, I wouldn't be able to do what I do, and that would be tough'* (320).

3.5.4 Uncertainty about the future subordinate theme 4: Worry of donor's future health

The previous subordinate themes have reflected participants' thoughts regarding their own future. The theme 'worries of the donor's future health' captures the anxieties experienced by participants towards the donor's prognosis. A sense of responsibility that participants may have affected their donor's health is conveyed in these excerpts.

Caroline: *'I do think quite a lot about, y'know, what if her kidney fails, what would I do because I've had her kidney and she'd be on dialysis'* (780).

Rose: *'I don't want the kidney to fail. It would be all my fault I think'* (734).

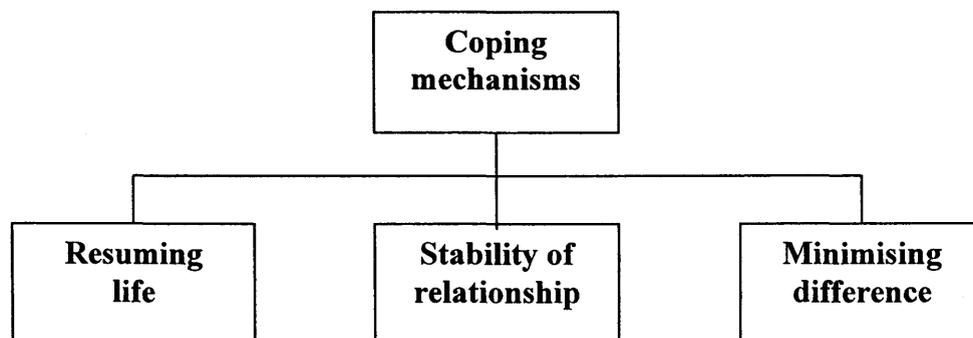
Worries regarding the donor's health are not solely focused upon their future well-being. Concerns of the donor's current health are also present.

Edward: *'It was traumatic, erm, to thin, that, y'know, erm, you have taken this kidney away from your son, especially your youngest son anyway, erm, and it was um (long pause) 'have I, have I damaged him in anyway?'* (418).

3.6 Super-ordinate theme 4: Coping mechanisms

This theme describes the coping mechanisms adopted by participants following transplant. They serve the purpose of assisting recipients to make the transition between an ill patient, and a healthy member of the community, providing a degree of normalisation and re-integration to pre-existing lifestyles. Figure 7 depicts the subordinate themes that constitute this theme.

Figure 7: Coping mechanisms - diagram of subordinate themes



3.6.1 Coping mechanisms subordinate theme 1: Resuming life

Shortly after transplant, participants had been keen to resume their life as it had been pre-procedure. They reflected upon their eagerness to continue with daily life soon after transplantation. This coping mechanism was used to encourage feelings of normality and continuation with life post-surgery, and may have helped challenge beliefs of self-regard as an ill, or unhealthy, individual.

Rose: *'I just wanted to get home and get back to my normal life, just to get on with things'* (157).

Caroline: *'I went back (to work) after the first month because I just couldn't stand it, couldn't stand being at home, just sitting watching daytime tv, boring little world'* (1118).

Participants required a degree of self-motivation to resume life, forcing themselves to continue despite not feeling entirely prepared.

Kate: *'I just was basically you know I felt really (pause) tired all the time and stuff but then I managed to get used to it and everything so but I went back to college like, I think it was about a week after I had my transplant'* (147).

3.6.2 Coping mechanisms subordinate theme 2: Stability of relationship

In order to resume life as it had been pre-transplantation, participants tended to minimise any changes in the relationship with the donor following transplant. This may have been a way of controlling the many changes occurring elsewhere as a result of the procedure.

Interviewer: *'What was your relationship with your mum like before you had the transplant would you say?'*

Kate: *'Um it was about the same as after I'd had the transplant' (414).*

Interviewer: *'Could you describe your relationship with your brother now?'*

Linda: *'Yeah it's the same as before'*

Interviewer: *'You had the transplant?'*

Linda: *'The same' (385).*

When asked about his current relationship with his sister following transplant, Steven described the relationship:

Steven: *'I would say exactly the same as it was before' (645).*

Some recipients described that their relationship with the donor had changed. They were keen to emphasise that they had been close before the transplant and that the transplant had not drastically changed their relationship. However, there seemed to

be some difficulty expressing and elaborating upon comments made about the nature of the relationship post-transplant.

Caroline: *'We were very close before (the transplant) and are very close now but I couldn't really des (pause) I wouldn't say we're closer but it sort of a deeper relationship'* (501)

John: *'I think it (the transplant) brought us a lot closer together, and erm, which I, and I think my wife would say that as well, because we were home y'know 24 hours a day together and having gone through what we'd gone through, it just brought us really a lot closer together, not that we were far apart'* (174).

3.6.3 Coping mechanisms subordinate theme 3: Minimising difference

Recipients expressed their discomfort at others, particularly those who were less familiar, knowing about the transplant. They described their dislike at being regarded as different because of the transplant, and were keen to minimise any differences between them and others who have not experienced transplant. They did not wish to be regarded any differently following transplant. They considered the purpose of others knowing about the transplant, which, if regarded as unnecessary, evoked feelings of discomfort.

Kate: *'When my dad told a few people who I didn't know, I just, I don't like people knowing, if you know what I mean this is why, I don't see why they have to know...I get upset and angry about that'* (377).

Caroline: *'I didn't want everyone at school to know cos they didn't really need to know, I don't, I'm not, I don't want to be centre of attention'* (872).

Participants compared themselves to others in order to challenge their belief of being 'ill'. Often, a process of overcompensation occurred whereby participants exaggerated their health status in order to restore equality with others.

Linda: *'Sometimes with my relations doing, huh, doing my head in a bit, 'oh you've been ill' ...I'm 'nothing wrong with me, I healthier than you' y'know that's what I don't like, so I don't really like telling anybody that I've had a transplant because, it's like they look at you like you're, er, want sympathy off them'* (527).

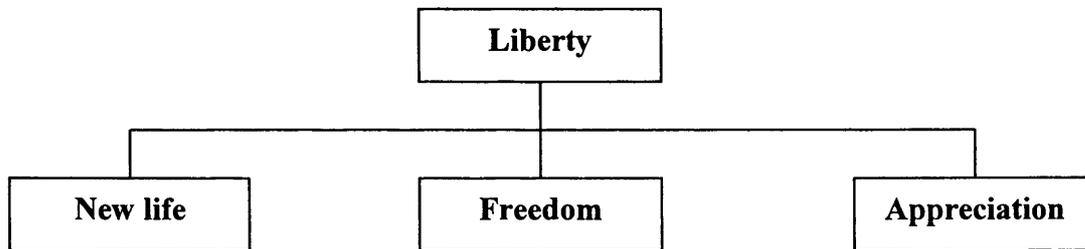
Reasons for not wishing others to know about the transplant are also related to difficulty reliving the experience when providing details.

Kate: *'I don't like them saying 'oh, are you alright?...going through it all again and telling them about it and stuff'* (389).

3.7 Super-ordinate theme 5: Liberty

The super-ordinate theme, liberty, captures the sense of moving on following transplantation, and the distinction made by participants between life pre- and post-transplant. The theme reflects the experience of a new life, or second chance at life due to the transplant. Freedom from dialysis, and a newfound appreciation for life and others are experienced.

Figure 8: Liberty - diagram of subordinate themes



3.7.1 Liberty subordinate theme 1: new life

Participants consider that the transplant has provided them with a new, or second chance at life. Perhaps life with kidney failure was considered to be over, due to its poor quality with the presence of dialysis, and the confrontation of thoughts of mortality. Following transplant, quality of life is significantly improved, and thoughts adapt to living rather than dying. The description of a new life suggests that a conscious division is made between pre- and post- transplant lives, perhaps useful as a coping strategy in detaching from the experience of transplantation, and encouraging a positive outlook to be adopted towards the experience.

Edward: *'You feel you've been given a new life'* (584).

Peter: *'You've got sort of another chance at a good life'* (680).

Linda: *'You'd been given a second chance with the kidney'* (251).

3.7.2 Liberty subordinate theme 2: Freedom

Participants described the experience of freedom following transplantation. They described liberty from illness and freedom in lifestyle. Quality of life following transplant is compared to the restrictions imposed by dialysis.

Caroline: *'You've got more freedom compared to being on a machine'* (812).

Linda: *'Going on holiday, not having to check in somewhere and have dialysis...you've got freedom'* (844).

Participants describe the ability to do more following transplant. This maybe associated with increased energy and feeling healthy, allowing for a more active lifestyle. They seem to consider that anything is possible.

Edward: *'Since I've had the transplant, I can do anything I want so to me it's absolutely fantastic'* (471).

John: *'Now we can do lots more y'know, things that we want to do'* (607).

3.7.3 Liberty subordinate theme 3: Appreciation

Participants reflect on a new appreciation for life and others following the procedure. This consideration reinforces the suggestion of life being regarded with a

pre- and post- transplantation division, with participants describing a change in outlook following transplant.

Kate: *'I think I appreciate life more...and um I try to enjoy it more as well'* (278).

Caroline: *'I think we definitely appreciate each other a lot more now'* (563).

Feelings of appreciation of life are related to feeling fortunate at having been afforded the procedure, and to be continuing life, regardless of the time since transplantation. Being ill, and experiencing transplant, prompts a re-evaluation of life.

Linda: *'More aware of life, and like er how great, how lucky you are, cos before...you have an illness you think oh nothing y'know, but if you'd been ill...you realise how precious it is, yeah and how lucky you were'* (491).

Steven: *'Took a whole different outlook on life because I realised I was fortunate to have gone through what I've gone through, or I felt fortunate, erm I was doing things'* (963).

4.0 Discussion

The study was designed to examine recipients' experiences of living-related renal transplantation. The results suggest that participants experience a variety of stages from diagnosis of kidney failure to recovery from transplantation, accompanied by a range of emotional responses.

4.1 Super-ordinate theme 1: Story of Illness

Participants describe the process of diagnosis of kidney failure to anticipation of the transplant as a sequential story. The representation of participants' experiences as a narrative is found in other research such as Bruner (1986). The representation of accounts as a story places participants in the centre of their experience (Freedman & Combs, 1996). The consideration of accounts as a story also represents their emotional expression, and accurately conveys the lived experience (Bruner, 1986).

Research examining living-related renal transplantation has examined distinct aspects of pre-transplantation experience such as the impact of being dialysis-dependent (Martin-McDonald, 2003), and responses to diagnosis (Gulledge *et al.*, 1983). A number of small, qualitative studies have examined overall recipient experiences some years after transplant (e.g. Simmons, 1983) concerned with post, rather than pre-transplantation accounts. Previous research has failed to acknowledge and explore stories or accounts from diagnosis until transplant. Longitudinal research would provide opportunity to study experiences pre- to post-transplant, allowing for the measurement of any changes over time. This is

discussed in section 4.1, further research. The present study asked participants to 'tell me a little bit about yourself and a brief history of your kidney problem from when it started to when you had the transplant'. This may have encouraged responses which are representative of a story. However, the distinct subordinate themes arose from participants' own accounts and were not shaped by the researcher.

Participants described feeling healthy soon after transplantation, therefore the 'story of illness' super-ordinate theme incorporates experiences whilst participants consider themselves to be ill, i.e. pre-transplant. Two participants experienced complications post-surgery, and therefore did not consider themselves to be healthy. The remainder of participants, however, referred to being and feeling healthy, and this was considered an end point to the 'story of illness' theme.

4.1.1 Story of illness subordinate theme 1: Diagnosis

Participants who were diagnosed with kidney failure and informed of the urgent need for a transplant reported feelings of shock, whether explicit, or inferred from a lack of emotional response. This may be indicative of the numbness experienced whilst in shock. Initial shock is a common response to the diagnosis of renal failure and the treatment implications of the illness (Gorman & Anderson, 1982). Although identified during quantitative studies, shock has not been explored in similar detail to the present study, and its relevance on the experience of transplantation has also been neglected. The finding contributes to a more comprehensive understanding of the experience of transplantation, in line with the aims of the present study.

Chronic renal failure frequently causes uraemic encephalopathy (Evers *et al.*, 1998). Haemodialysis also appears to perturb this condition (Kramer *et al.*, 1996), which alters brain function and structure in the presence of renal failure. This can result in loss of memory and cognitive ability, impaired concentration, fatigue and irritability (Longmore *et al.*, 2004). The effects of uraemic encephalopathy could impair understanding and absorption of information at time of diagnosis, or when informed for the need for a transplant. This may result in a lack of expressed emotion.

Those who had received diagnosis some time ago had been informed of a future need for a transplant. The lack of urgency for a transplant, and the long time period since diagnosis to adjust gradually to the prospect, may be responsible for participant responses being practical and lacking emotion when told of the current need for a transplant. The lack of an expressed response could be due to the presence of secondary alexithymia, the difficulty in verbalising emotions, when confronted with renal failure and future living-related renal transplantation (Fukunishi *et al.*, 2002).

It has been suggested that a lack of expressed response to kidney transplantation may be a mechanism for coping with the concept of transplantation (Adler, 1972). Andrew's (1970) model of coping styles suggests that patients respond to information preparing them for potentially stressful medical procedures with two different coping styles. Vigilant copers acknowledge the negative emotions that accompany the procedure, whereas repressors or avoidance copers deny thoughts about the negative aspects of the situation. The types react differently to preparatory

information about surgery. When given specific information about the procedure, the avoiders tend to do worse than when they are given no information or only general information. Active copers, however, do better when given specific information, suggesting that coping style and type of information about the procedure interact. The relevance of the way in which information is conveyed and the implications for clinical practice is discussed further in section 4.6, clinical implications.

4.1.2 Story of illness subordinate theme 2: Being offered a kidney

None of the participants approached potential donors upon being informed of the need for a transplant. All participants were offered a kidney by a relative. Simmons and Klein (1972) found that recipients felt they should not ask their relatives for a kidney, for fear of significant role changes and disruptions within the family unit (Conrad & Murray, 1999). Participants did not describe contemplating asking for a kidney, as family members readily offered them. Simmons *et al.* (1971) suggest that the crisis condition of a family member requiring a transplant forces a relative to offer a kidney. Up to 20% of donors report feeling coerced into donating (Simmons *et al.*, 1987). Failure to request a kidney, may be reflective of the involvement of cultural factors which can influence the request process. In contrast to the west, in Japan recipients are more proactive and solicit their relatives (Ota, 1994).

Donors were found to feel responsible for making the decision of who was most appropriate to be a donor, encouraged by recipients who passed the responsibility to them. Decisions regarding who should donate appear to be based upon previous

relationships with the recipient (Janosik & Green, 1992), the wish to reconcile self with the recipient (Kempf *et al.*, 1969), the donor wanting to boost self-esteem (Fellner, 1976), or to fulfil the basic desire of wanting to give (Fellner, 1976). Systemic family working with health professionals may serve to prevent donation occurring due to questionable reasons (Kempf *et al.*, 1969). It may also assist communication between family members regarding expectations of the donor. This is discussed in further detail in section 4.6, clinical implications. Future research may examine the experiences of individuals who chose not to donate a kidney in order to learn of the processes involved in the decision.

4.1.3 Story of illness subordinate theme 3: Anticipation

Participants expressed anticipation regarding transplantation either as looking forward to the procedure in order to cease dialysis, or with anxiety at the perceived enormity of the surgery. The anticipation of ending treatment via dialysis may be due to its experience. This is described by recipients as a punishing struggle (O'Hara, 2001), potentially generating feelings of anger, depression and hopelessness in patients (White *et al.*, 1990). Martin-McDonald (2003) identified feelings of long-standing hope in dialysis patients for a transplant which may enhance feelings of anticipation once the preparation for transplant had begun. Anticipation has not been identified or explored in previous studies as a separate entity, although responses of anxiety, arguably distinct from apprehension, exist. The identification of anticipation concurs with the aim of the study by adding new findings to the existing body of research.

Participants described fears of surgery and pain, previously acknowledged as common anxieties among potential kidney recipients (Gulledge *et al.*, 1983). The procedure is recognised as a prominent source of anxiety (Dubovsky & Penn, 1980). It can be aggravated by distress about financial problems, inability to work and sexual dysfunction (Starzl *et al.*, 1977). Taylor (1979) theorises that anxiety regarding the procedure is related to fearing loss of control, applying to three aspects: loss of normal control of one's body, loss of typical activities such as work, and loss of ability to predict what will happen. The inability to forecast the course of the illness or to predict what will happen appears to cause significant anxiety (Bennett & Disbrow, 1993). It is consistent with evidence that people respond to aversive experience with more discomfort and anxiety when control is perceived to be low, than they do when the situation is equally unpleasant but under their control (Glass & Singer, 1972).

Research suggests that the more information a patient has about the surgery before it takes place, the least distress they will experience at the time of the procedure (Galloway & Graydon, 1996). In order to minimise apprehension, pre-operative information and education groups could be provided. The clinical implications of this finding are discussed in further detail in section 4.6.

4.2 Super-ordinate theme 2: Kidney as a gift

Participants described the donated kidney as a gift, reflecting ideas within the super-ordinate theme of the gift exchange paradigm (Mauss, 1954). Mauss suggested that the act of giving is a form of contact that has social norms attached.

The notion of a gift carries potentially complex and contradictory meanings which can have unexpected effects on those involved in the gift relationship (Tutton, 2002). Gift exchange involves obligations to give, receive and repay, reflective of this subordinate theme.

4.2.1 Kidney as a gift subordinate theme 1: Ownership of kidney

Participants' opinions of the current owner of the transplanted kidney appear to be dictated by the nature of the relationship with the donor. Some viewed the transplanted kidney as their own as it had been explicitly given to them by their donor. Taking ownership of the kidney may have been influenced by the manner in which the donor offered and discussed the donation with the recipient. It is valuable to determine the background and meaning of the donation and acceptance attributed by recipients. These can then be addressed and any related problems such as guilt, loss and depression might be lessened (Vernale & Packard, 1990).

Participants report the kidney as the donor's when in the donor's presence, and as their own in the donor's absence. This may serve to remind the donor that the act of donation, for which the recipient is grateful, has not been forgotten. It may be reflective of a relationship whereby the discourse of a 'gift' is greatly held (Sque *et al.*, 2006). Gerrand (1994) states that the discourse of the kidney as a gift has highlighted that the body is not property which can be owned or traded. This may be representative of the conflict which some participants experience, shifting between stated owners of the kidney. Amalgamation of ownership arose within spousal relationships whereby kidneys were considered to belong to both recipient and

donor. Conflict and amalgamation may be illustrative of difficulties integrating the kidney into the self, whereby the recipient has a psychodynamic perspective and not yet fully assimilated the organ into their own internal body image and ego (Muslin, 1971). Further research examining the impact of transplantation on family members, including the donor, may identify who they consider to be owner of the kidney. This would allow for the comparison of beliefs held by recipients and family members and aid understanding of their development. This is discussed in section 4.8, further research.

4.2.2 Kidney as a gift subordinate themes 2, 3, 4: Feeling grateful, desire to repay donor, inability to repay donor

The three subordinate themes will be considered concurrently, due to their interconnectedness. All participants explicitly described feeling grateful to their donor, again a construct commonly expressed within transplant literature (Sanner, 2003). Sense of gratitude has been found troublesome to manage (Sanner, 2003). It can be a major source of stress within a family due to constant attempts made by the recipient to restore a perceived imbalanced relationship (Simmons *et al.*, 1977). Participants articulated a desire to repay their donor, often using financial means, a method frequently adopted by recipients (Sanner, 2003). Paradoxically this was also considered an inadequate method of repayment, and participants expressed their hopelessness and continuous search to convey their gratitude sufficiently. A desire to repay the donor serves to restore the imbalance within the relationship, and has been associated with feelings of debt for the recipient (Fox & Swazey, 1974). However, the inability to reciprocate a gift of equal value can create disturbing

psychological disturbance for both the recipient and the donating family (Sque *et al.*, 2003). Feelings of imbalance can often be resolved by consideration of the donor gaining from the donation, e.g. high self-esteem and admiration from others (Sanner, 2003).

Working systemically with families may serve to assist management of any imbalances within the relationship. It could provide opportunity to have facilitated discussion of issues of gratitude and ways in which this may be resolved. This is discussed further in section 4.6, clinical implications.

4.2.3 Kidney as a gift subordinate theme 5: Taking care of kidney

Participants described several reasons for taking care of the kidney. They expressed an obligation because it was given, and entrusted, to them. This may illustrate to the donor that care is being taken by displaying gratitude and respect for the donor's act. Feelings of obligation may arise from donors' expectations that recipients will assume responsibility for maintaining a healthy life style (Conrad & Murray, 1999).

Participants report the need to look after the kidney and when under potential threat, the desire to protect it. Both may serve to actively prolong the life of the kidney, and subsequently their life, and guard themselves against dialysis. Anxiety of potential loss of the kidney is frequent (Tanriverdi *et al.*, 2004) and may encourage participants to take care of their kidney in order to minimise risk of loss.

The theory of reasoned action (Ajzen & Fishbein, 1980) may explain why recipients take care of their kidney. It assumes that the determinant of behaviour is peoples' intention to perform that behaviour. Behavioural intentions such as wanting to take care of the kidney are a function of a person's attitude towards the behaviour. This is determined by their belief that the behaviour will lead to a positively or negatively valued outcome. Behavioural intentions are also a function of a person's subjective norm. This is shaped by their perception of the value that significant others place on that behaviour and by their motivation to comply with those norms. In this case, recipients may take care of the kidney due to beliefs that they are fulfilling the donor's expectations to do so, perceiving the action to be highly valued by the donor. They may also be motivated to take care of the kidney due to feelings of gratitude and the belief that doing so will prolong the kidney's duration. The theory can also be used to predict adherence to health-related behaviours involved in taking care of the kidney.

By providing post-operative information about how to look after and maximise the life of the kidney, recipients may feel less responsible for taking care of the kidney. They may instead place this on to those health professionals making the recommendations. This would reduce recipients' preoccupation of taking care of the kidney and is discussed further in section 4.6, clinical implications. Future research could repeat the current study with donors rather than recipients in order to determine whether donors obligate recipients to take care of the kidney. This would inform the development of recipients' beliefs about taking care of the kidney, and is discussed further in section 4.8.

4.3 Super-ordinate theme 3: Uncertainty about the future

Participants reported a variety of uncertainties about the future: longevity of the kidney, availability of a future kidney, restrictions of dialysis and worry regarding the donor's future health. These uncertainties about the future, believed to be symptomatic of a fear of rejection of the kidney, can be maintained by potential implications of the loss for the recipients' life (Baines & Jindal, 2003).

Uncertainty about the future is highly stressful (Sutton & Murphy, 1989), and may be a manifestation of recipients' belief they have little control over their body's acceptance or rejection of the kidney (Frey, 1990). It can cause deterioration in mood, leading to medical non-compliance (Baines & Jindal, 2003). Heart transplant recipients' non-compliance with post-transplant treatment has been linked to depression in those who experienced graft rejection (De Geest *et al.*, 2001). Low mood may evoke feelings of hopelessness, forgetfulness, anhedonia and a lack of motivation and energy (Hawton *et al.*, 1989). These in turn may impact on the physical taking of medication, and distort thoughts regarding the utility of medication. Research regarding the predictors of response to transplantation using regression analyses may identify characteristics or experiences which result in high levels of uncertainty. This is discussed in section 4.8, further research.

The clinical implications of uncertainty are addressed in detail in section 4.6. However, the role of health professionals in providing information, reassurance and opportunity to express uncertainty may serve to manage it effectively. The sharing

of experiences within a group setting post-transplant may normalise uncertainty as well as providing strategies to minimise its impact.

4.3.1 Uncertainty about the future subordinate theme 1: Longevity of kidney

Participants expressed uncertainty regarding the longevity of the kidney. They speculated upon potential time spans for the kidney's survival, based on reports of fellow recipients' experiences, rather than their consultant's opinion. Recipients can experience difficulty tolerating the uncertainty of the longevity of the kidney. As a result, they may often spend time searching for certainty in other aspects of their lives (Baines & Jindal, 2003). Participants who underwent transplant some time earlier continued to feel uncertain about the kidney's longevity. Although preoccupation with rejection and when it may occur diminishes over time, it remains significant five years post-transplant (Fallon *et al.*, 1997).

The precaution adoption process model (Weinstein *et al.*, 1998) illustrates the process of recipients' beliefs about personal susceptibility to transplant failure, and offers explanations as to why attempts to prevent kidney failure are made. The model assumes that when people feel they must keep themselves from harm, they go through several stages of belief about their personal susceptibility in order to realise a way to protect their health. In stage one, people have not heard of the hazard i.e. losing the kidney. In stage two, they are aware of the hazard and believe that others are at risk, holding an optimistic bias of their own level of risk. Personal susceptibility is acknowledged and recipients accept the idea that precaution would

be effective, but have not yet decided to take action during stage three.

Contemplation of the longevity of the kidney may occur at this stage of the model.

At stage four, people decide to take action such as planning the possibility of a future transplant, or beginning the process of locating a future potential donor. At stage five, action is often deemed unnecessary but precautions aimed at reducing the risk of kidney failure, such as taking care of the kidney, take place at stage six. The maintenance of these precautions occurs at the final stage of the model. The following subordinate theme regarding the availability of a future kidney occurs during stage four.

4.3.2 Uncertainty about the future subordinate theme 2: Availability of future kidney

Participants reflected upon uncertainty regarding the availability of a future kidney, assuming that a second transplant would be required in the future. Some had not considered the origin of a future kidney, and expressed feeling depressed at the uncertainty of a kidney's availability. For those who had considered a potential future donor, uncertainty about compatibility and matching was a source of anxiety. These recipients tended to be female. Others, mostly male recipients, were reassured that their children would have a suitable kidney, with an assumption that the donor would supply the kidney without question. Further research could examine the effects of gender on the experience of transplantation in order to identify any significant differences between the genders. This is discussed in section 4.8, further research.

Cognitive theories understand anxiety as a response to the selective processing of information perceived as a threat or danger to personal safety or security. For example, the risk of illness or loss of kidney (Beck *et al.*, 1985). Cognitive-behavioural theories of health anxiety suggest that those who are anxious about their health are more likely to consider themselves at greater risk of illness. This may subsequently increase anxiety (Hadjistavropoulos *et al.*, 1998). Therefore, participants who are anxious regarding the need for a future kidney and its availability may have a tendency to perceive themselves at more risk of illness.

Baines *et al.* (2002) express recipients' need to cultivate points of certainty in their lives when experiencing uncertainty regarding their kidney. Perhaps consideration or planning of the availability of a future kidney, serves as a way of providing certainty and predictability, therefore reducing anxiety.

4.3.3 Uncertainty about the future subordinate theme 3: Restrictions of dialysis

Contemplating the future, participants considered dialysis to be restrictive of lifestyle. This was in comparison to the perceived freedom provided by a transplant. The uncertainty of dialysis' necessity provoked outspoken statements of the dislike of dialysis. Participants were adamant that they would not welcome its return. The majority of current participants had received dialysis pre-transplant, and may have experienced poor quality of life (Molzahn, 1991), a desire to control events and decisions (Corbin & Strauss, 1987) and feelings of despair (Martin-McDonald, 2003). It is therefore understandable that recipients would not wish to re-encounter

these experiences. Such extreme responses to the thought of future dialysis may be a reflection of the hope of success placed on the new kidney, which may be unrealistic and unable to fulfil their expectations.

4.3.4 Uncertainty about the future subordinate theme 4: Worry of donor's future health

Participants experience worry regarding their donor's future health. This has been acknowledged as a common source of anxiety to recipients (Fukunishi *et al.*, 2002). The present study places this anxiety within the context of the overall experience of transplantation, highlighting when recipients' may perceive the highest level of anxiety. Participants described concern for their donor's current and future health, based upon worries that the donor will become ill some time after surgery. This process of worry appears to begin pre-transplantation (Sanner, 2003). Participants expressed a degree of responsibility for their donor's health. This was related to feelings of guilt at removing a healthy kidney which may be needed by the donor. Not unique to recipients of a kidney, the emotional disturbance of anxiety regarding the donor's health has been identified in bone marrow transplant recipients (Lesko, 1994). Living-related liver recipients have also reported anxiety post-transplant once the threat of their own death has subsided (Fukunishi *et al.*, 2002).

4.4 Super-ordinate theme 4: Coping mechanisms

Recipients implemented a range of coping mechanisms to assist re-integration to life pre-transplant, and as a means of promoting belief in being a healthy individual

comparable to others. These beliefs appeared implicit and were inferred from accounts rather than explicitly stated.

Previous studies have examined mechanisms for coping following kidney transplantation (Adler, 1972). Mechanisms have been considered to assist adaptation to new surroundings by maintaining intrapsychic balance. They aid mastering of the environment, providing relief from post-transplant anxieties (Adler, 1972). Coping strategies are often implemented to enhance feelings of control as demonstrated by Wittenberg *et al.* (1983) who found associations between perceived control and positive coping in haemodialysis patients. Control strategies have been associated with illness role, degree of disability, perceived handicap and achievement of rehabilitation goals (Viney & Westbrook, 1982).

Miller's (1983) study of chronically ill hospitalised adults suggests that denial, repression and suppression are the most frequently used avoidance-coping strategies. The most frequently used approach-coping strategies included seeking information, enhancing spiritual faith, diverting attention and expressing feelings and emotions. The more coping mechanisms used, the greater the degree of stress experienced by recipients (White *et al.*, 1990). Therefore, the use of many coping mechanisms may be symptomatic of difficulties being experienced post-transplant. It is important that these be managed by providing opportunity and support to discuss concerns perhaps in a post-transplant care group setting. This is discussed further in section 4.6, clinical implications.

4.4.1 Coping mechanisms subordinate theme 1: Resuming life

Participants expressed the need to resume life to how it was before kidney failure. An impatient desire was expressed to take up previous lifestyle and commitments as soon as possible. This was often in conflict with the physical demands of recovery, and required a degree of motivation to execute. Resuming life may act as a coping mechanism to challenge the belief of being ill and its consequences of potentially feeling weak, dependent and inadequate. Recipients are keen to regard their body as healthy and 'normal'.

Sanner (2003) similarly observed that recipients make an effort to normalise their transplanted body. This is understood as a means of forgetting about the transplant, which may be equally valid here. By resuming life to a pre-transplant dynamic and schedule, thoughts of the transplant may be distracted, the transplant forgotten, and the presence of the self-belief of being healthy and 'normal' reinforced.

4.4.2 Coping mechanisms subordinate theme 2: Stability of relationship

Coping mechanisms are argued to facilitate equilibrium (Adler, 1972). When disturbed, there is potential to upset the donor-recipient relationship due to the imbalances of power and indebtedness resulting from donation (Mauss, 1954). However, many participants did not report changes in their relationship with the donor from pre- to post- transplant. This expression of equilibrium may indeed be genuine, and serve as a coping mechanism for maintaining equilibrium within the relationship. It may also reflect denial or wish fulfillment. Findings suggest that

recipients wish their relationship with the donor to be unchanged (Sanner, 2003). This wishing may serve to explain the dissonance of reports between inferred imbalances, and subsequent changes within the relationship due to feelings of gratitude. It may also elucidate reports that the relationship remains stable. Recipients appeared resistant to reflect on their relationship, which may indicate difficulty coping with the gift relationship. Since interviews in the present study were not therapeutic, dissonances and resistance were not pursued in great depth. It felt inappropriate to question and challenge coping strategies without opportunity to assist the adaptation to new, more effective strategies.

4.4.3 Coping mechanisms subordinate theme 3: Minimising Difference

Participants were keen to minimise differences between themselves and non-transplanted individuals. This appears to serve as a coping mechanism for recovery by normalising experiences and assisting resumption with life. Feelings of discomfort were experienced when unfamiliar individuals were informed of the transplant, for fear that they would treat the recipient as special or different. Recipients were reluctant to disclose details of the procedure as this evoked the re-living of the experience. Recall of the transplantation process is easily cued within recipients (Sanner, 2003). Therefore it is understandable that recipients would not wish to access thoughts possibly associated with pain or fear. Distancing and detaching oneself from others has been identified as a coping mechanism in kidney recipients (White *et al.*, 1990). It may serve as a way of avoiding self-comparisons with healthy individuals which would highlight illness and difference. It may also

allow recipients to avoid becoming engaged with others in conversation regarding the transplant.

Berg *et al.* (1998) propose a social-contextual model of coping. This is particularly relevant when considering the minimisation of differences which occur when comparisons are made to others within the social context inhabited. The model (Berg *et al.*, 1998) suggests that individuals cope at numerous levels, from a solely individual appraisal of the problem, to integrated appraisals made with and by others. Within their social context, recipients inevitably compare themselves to others. This is then followed by an individual appraisal which minimises their differences and serves as a way of coping with the perceived differences.

Existing research fails to identify the ways in which individuals specifically attempt to minimise difference. This is in contrast to the present study which concurs with its aim of adding to the existing research by providing detailed understanding of the experience of transplantation.

4.5 Super-ordinate theme 5: Liberty

Liberty captures the sense of moving on following transplantation. It reflects the positive outcomes of the transplant and illustrates how recipients make sense of their lives post-transplant, whilst embracing their new health status. The theme suggests freedom and relief from dialysis and illness, allowing progression and continuation with life.

4.5.1 Liberty sub-ordinate theme 1: New life

Participants reported that the transplant had provided them with a new life. The theme of a new life, or rebirth, is frequently voiced with the literature (Buldukoglu *et al.*, 2005; Simmons *et al.* 1977). It is most prominent when the transplant process has been uncomplicated and resulted in good kidney function. The process is thus regarded as valuable (Simmons *et al.* 1977). If recipients feel that their pre-transplant life has been restricted due to illness, they may consider post-transplant life to be a potentially successful second opportunity for living their lives as they wish (Rapaport, 1973).

4.5.2 Liberty sub-ordinate theme 2: Freedom

Research highlighting improvements in quality of life following transplantation emphasises the importance of freedom a transplant provides compared to dialysis (Simmons, 1983; Tanriverdi *et al.*, 2004). Participants reported new freedom in lifestyle and liberty from illness, providing the ability to live their lives as they wish. Dialysis patients hope for their lives to become less restrictive, with more control which is not mediated by health care professionals (Martin-McDonald, 2003). Long-term hope and desire for emancipation may serve to enhance the sense of freedom experienced post-transplant and augment appreciation.

4.5.3 Liberty sub-ordinate theme 3: Appreciation

Participants reflected on a newfound appreciation for life following transplant. They reported feeling fortunate to have had the transplant, and made attempts to enjoy life. It is commonly reported that long term appreciation of life is greater in kidney recipients than in the general population (Conrad & Murray, 1999; Simmons *et al.*, 1987). This may be because the experience of being close to death due to kidney failure, gives an enhanced awareness of fragility of life (Simmons *et al.*, 1987).

4.6 Clinical Implications

A number of clinical implications arise from the research, some of which relate directly to recipients, whilst others extend to the role of health care professionals.

4.6.1 Conveying of information by health professionals

The findings suggest that diagnosis of kidney failure, and being informed of the need for a transplant, evoked responses of shock. Since shock can divert attentional resource (Pally, 1998), information may not be adequately absorbed and understood. Recipients may therefore be unable to recall essential information regarding the procedure, resulting in confusion and misunderstanding.

In order to minimise misunderstanding resulting from shock reported by participants, the breaking of news of the need for a transplant could be addressed

using the evidence based intervention of the 'six step protocol for delivering bad news' (Baile *et al.*, 2002). Doctors sharing diagnoses could adhere to the protocol designed to assist the breaking of bad news, in order to maximise patient understanding and promote empathy. Designed for use with cancer patients, its principles are relevant to other chronic illnesses. The intervention would reduce miscommunication and misunderstanding about the prognosis or treatment available (Weeks *et al.*, 1998). Inadequate information may produce unrealistic expectations of the process and greater risk of dissatisfaction (Ozcurumez *et al.*, 2004).

4.6.2 Pre-operative information and education

The findings of the current study highlighted feelings of anticipation pre-transplant. In preparing for stressful medical procedures, evidence suggests that the more information a patient has about the surgery before it takes place, the least distress they will experience at the time of the procedure (Galloway & Graydon, 1996). In order to minimise distress, pre-operative education groups could provide a safe environment for recipients to share and normalise anxieties regarding surgery or pain, whilst providing anxiety management strategies. Those who have difficulty expressing fears could be encouraged to verbalise their anxieties and be provided with techniques to assist their management. Awareness of strategies may increase perceived degree of control over anxiety, subsequently causing a reduction in its intensity (Rapee *et al.*, 1996). Consultation with staff involved in patient care regarding the presence and indicators of un verbalised feelings before transplant could ensure their identification. This would assist patients in receiving the support required (Lampic *et al.*, 1996). A screening process could also assist identification

of patients who may require assistance. Alerting recipients to commonly experienced difficulties prior to transplant could offer opportunity to explore coping mechanisms available to deal with these, should they arise.

The current study found that the fear of losing a kidney was experienced. Pre-operative consultation may identify individuals with long standing or unresolved psychological issues who may be more vulnerable to anxiety regarding the loss of the kidney. It could also be useful to those who may struggle with the process of transplant. Wagner *et al.* (2001) consider that the identification and management of chronic illness and psychological needs can be effectively carried out with the use of a care plan approach. These could be developed and individuals provided with appropriate and continuous psychological support

4.6.3 Role of health professionals

Health professionals involved in recipient care can help to manage the experiences highlighted in the present study, both pre- and post-transplant. They could offer recipients opportunity to express concerns and provide reassurance regarding any anxieties whilst under their care. Assurance that they will be regularly reviewed and consultation available should any concerns arise, may serve to promote feelings of independence and freedom, minimising dependency on services. Austenfield & Stanton (2004) consider that patients gain comfort from regular contact with health professionals following a surgical procedure.

Recipients should be provided with adequate opportunity to clarify information regarding process of donation, possible effects of donation for the donor, surgery, pain control, and prognosis of the transplant. During consultation, advice could be given and repeated to ensure its absorption, informing recipients about what they can do to look after and maximise the life of the kidney. Consultation could also provide realistic expectations as to the life span and limitations of the organ.

Shuldham (1999) demonstrated that pre-operative information engenders confidence in the opinions of medical staff. In the current study, recipients gained information from fellow recipients regarding kidney life span.

The presence of internet chat rooms for kidney recipients suggests that they find discussing their experiences to be beneficial (Morris & Ogan, 1996). A chat room facilitated by the Organ Transplant Association aims to educate by collecting and posting information. This creates a sense of community and allows the sharing of experiences. It also serves to provide information on the interests, concerns and needs of recipients.

Reassuring recipients about the availability of options should the transplanted kidney fail in the future, would provide a degree of predictability and subsequently reduce anxiety. Schofield *et al.*, (2003) found that being involved in treatment options, and being reassured of alternatives should the initial treatment fail, resulted in higher levels of control and self-efficacy among patients. By feeling they are pro-actively doing all they can to look after the kidney, including finding out information from fellow recipients to help preserve the kidney, they may feel they

are helping to prolong its lifespan. This may reduce anxiety regarding uncertainty of the future.

4.6.4 Systemic working

Irresolution of the ownership of the kidney, and issues arising from feeling grateful, such as the inability to repay the donor and the obligation to take care of the kidney, were identified in the current study. Pre-transplant facilitated discussions with family members can enhance post-transplant outcome in terms of donor-recipient relationships (Simmons *et al.*, 1987). They can be helpful in ensuring that donors do not feel coerced (Simmons *et al.*, 1987) and can attempt to mitigate disruptions within the family (Conrad & Murray, 1999). Working systemically with families could prevent donation occurring due to questionable reasons, such as the donor wishing to reconcile with the recipient (Kemph *et al.*, 1969), or the donor wishing to boost self-esteem (Fellner, 1976).

Systemic working may serve to assist communication between family members regarding expectations of the donor, consideration of ownership of the kidney post-transplant and in redressing imbalance within the relationship due to the gift exchange. Encouraging the explicit expression of the recipients' concerns of the donor's health with the donor may provide reassurance to the recipient, whilst modelling a method of communication that family members can implement in the future. The presence of family members could provide opportunity to air the concerns of relatives regarding the impact of transplant. Expression of family members' thoughts regarding a second, future donation may reduce recipient

anxiety regarding the origin of a future kidney. Systemic working with families beginning at diagnosis and continuing throughout recovery has been found to be more effective than therapy commenced during the recovery period (Burbatti *et al.*, 1993).

4.6.5 Post-transplant care

The study highlights the presence of uncertainties following transplant regarding the future, the loss of the kidney, return to dialysis and worries regarding the donor's health. Evidence suggests that to aid feelings of uncertainty, recipients could be assisted to create a degree of certainty and predictability in other aspects of their lives (Baines *et al.*, 2002). This could be done with the help of health care professionals such as occupational therapists who can help recipients to set and achieve small goals, affirming certainty and predictability in some aspects of their lives. Reassurance that a degree of uncertainty is commonly associated with transplant (Sanner, 2003) would serve to normalise feelings.

Sharing uncertainty and experiences within a group setting post-transplant might lessen dependency on services, and encourage freedom for those who experience difficulties resuming life post-transplant. Redefining normality in terms of social, relational, vocational and recreational lifestyle post-transplant, whilst highlighting that the past cannot be recaptured and that illness often changes personal attributes and perspectives, may further assist recipients (Baines *et al.*, 2003). The personal nature of this work dictates that it would be most appropriately addressed within a therapeutic, or at least, trusting relationship.

4.7 Critique and limitations

The present study contributes to a field in which little is known of the experiences of living-related renal recipients. It has implications for those considering transplantation, health professionals and the transplant services in which they work. The aims and methodology of the study were clearly defined, and the research considered in respect to the criteria recommended for qualitative research (Elliott *et al.*, 1999).

Interpretative Phenomenological Analysis (IPA) seeks to examine and interpret the meaning participants make of their experiences. However, limitations of the methodology exist. Data sourced from interviews have been criticised for their reliance on the participant's ability to articulate their story (Willig, 2001). How reliable an individual's experience can be reflected within the overall findings is questionable. The methodology did not account for differences in time since transplantation, with recipients having received a transplant between twelve months and nine years previously. The variations in time period, and therefore time to adjust to transplant may have affected the results. Benefits of the methodological approach used in the study were felt to outweigh limitations particularly in its ability to produce a narrative account that reflects the experiences of living-related renal recipients.

Findings are a product of both the participant and the researcher. The researcher's own understandings and perspectives will therefore influence the analysis of the data. The researcher was aware that her gender, age, social background, professional

role, experiences of her own and family members' illnesses, would have an impact on the process. This is reflected upon in detail with the critical appraisal (Section C).

A number of credibility checks were used in order to scrutinise the analytic process, in accordance with Smith's (2004) guidelines. This included the coding of anonymised transcripts by members of a qualitative research. Credibility checks are further detailed in the critical appraisal (Section C). Discussion of the findings with the participants after analysis may have been valuable. However, due to time constraints following a delay in ethical approval, this was not feasible. The delay and impact of gaining ethical approval is discussed in detail in section three, critical appraisal.

The study gained a rich and complex understanding of recipients' experiences of living-related renal transplantation. IPA was appropriately suited for reflecting recipients' experiences. It has been argued that other researchers should demonstrate that the findings can be generalised to other contexts, rather than placing the onus on a single qualitative study (Erlandson *et al.*, 1993). Therefore, it cannot be considered that the findings of the present study could be generalised. However, they can be considered in respect of good research criteria, defined by Salmon (2003) as the ability to: equip health professionals to think or act differently in the future; help to highlight new hypotheses; assist reconsideration of existing assumptions.

The study highlights experiences which have failed to be identified within the existing literature, and places them within the context of the transplantation experience. It describes the journey of diagnosis to transplant as a story of illness. Previous research has failed to represent or explore pre-transplant experiences as a story or narrative account. Shock at diagnosis has been identified in quantitative studies, but has not been considered to the extent to which the present study explores it and discusses its impact and implications. Previous studies have examined the role of anxiety, but have failed to distinguish apprehension as a separately occurring entity, unlike the present study. This research identifies, explores and presents the experiences of transplantation within a contextual framework, enhancing understanding for potential recipients, families of recipients and health professionals.

4.8 Further research

Few studies to date have investigated recipients' experiences of living-related kidney transplantation using an idiographic, qualitative methodology. Examining recipients' experiences by sampling a cohort who all received a transplant within the same year, followed by recurrent interviewing at set future points, could enhance the research further. It could serve to develop understanding of the adjustments and processes which occur over time.

A questionnaire based on the findings of this study and from a systematic literature review could be administered at regular intervals as a longitudinal study. This quantitative methodology would provide a less time consuming way of collecting

data over a long period. Longitudinal data permits measurement of differences or change over time and can be used to locate the causes of social phenomena in health psychology (Mehard, 1991), for example, Kronmal *et al.* (1993). Commencing pre-transplant, this study design, using a multiple regression analyses, could highlight predictors for response to transplantation such as coping strategies or anxiety. Such designs are commonly implemented within health psychology due to their ability to develop models for understanding behaviour (e.g. Katz *et al.*, 1998).

Research examining the effects of gender or ethnic background on the experience of living-related kidney transplantation, would be a further advance on the current research. Selected measures chosen to assess experience could be administered to groups, each consisting of similar individuals i.e. all male, or all white British. Using a post-hoc analysis, any significant differences between the groups would be highlighted. A study comparing male and female adolescents' health risk behaviour adopted a similar design (Hawkins *et al.*, 1999).

Within this study, the relationship with the donor and other family members is referred to. Future research may wish to extend the findings of this study by examining the impact of living-related transplantation on other family members, or to repeat the current study using a sample of living-related donors. Current evidence has examined the experiences of transplantation on the donor, for example Pradel *et al.* (2003). However, studies have generally employed a quantitative approach which has fragmented the experience. The overall impact of the experience has therefore been neglected.

Identifying the experiences of potential donors who chose not to donate would enhance knowledge of the decision making process and the family dynamics involved. A systematic review of the literature would note whether the research has previously been carried out in the area. A qualitative methodology may provide understanding of the process of donation from donors' individual accounts. Analysis using grounded theory technique may provide a model to illustrate the process, if this was appropriate. This is recommended by Annells (1996) and used in current research, i.e. Sanner (2003).

A few of the transcripts provided rich data, which could be examined as individual case studies, as suggested by Smith (2004). Smith (2004) acknowledges the value of detailed single case data, which can be informative due to the deeper analysis and interpretation which the methodology allows. Recent research in the area has neglected this design, perhaps due to its lack of generalisability. However, detailed reports can provide a complete analysis of an individual than can be obtained in an investigation with a sample of a larger size (Brannon & Feist, 2000).

A number of theoretical perspectives could be used to take this area of research forward. These include a humanistic perspective (Schaffer, 1978) which asserts that both behaviour and mental processes should be considered simultaneously. The consideration of processes and behaviour within the above future research ideas, could significantly enrich the findings. A systems perspective (Tyler, 1993), acknowledging the role and interaction between an individual and their specific socio-cultural environment, would provide a context for the interpretation of findings of future research.

4.9 Conclusion

The present study aimed to examine the experiences of recipients who had received a kidney from a living-related donor. It identifies, explores and presents the experiences of transplantation within a contextual framework. Currently, research regarding the overall experiences of recipients is negligible. Although the findings herein cannot be representative of all recipients, the study provides a greater understanding and appreciation of their experiences and psychological processes, from diagnosis through to resumption of life post-transplant. The research has implications for the understanding of transplantation, providing practical information for health professionals to support recipients throughout the process. The findings are therefore relevant to all health professionals interacting with potential or existing recipients, and families of recipients and donors. Awareness of the experiences of transplantation is essential if the benefits to living-related renal recipients are to be maximised.

5.0 References

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Section C

Critical Appraisal

Word Count (excluding references): 5032

1. Introduction to the Critical Appraisal

The critical appraisal is based on a research diary maintained throughout the research process which included initial ideas, responses to interviews, transcription and analysis, and thoughts regarding my influence on the research. The section is also informed by reflections apparent on completion.

2. Origins and planning of the Research

I became interested in the area of health psychology whilst working as an assistant psychologist in a medical psychology department. The post provided me with opportunities to work with individuals suffering from a range of chronic illnesses, including renal failure. Having developed an interest in health psychology, I approached my allocated supervisor to determine whether she had any ideas about research in the area, which she would like carried out. Discussions took place regarding suggested topics, including cardiac rehabilitation, diabetes and living-related renal transplantation. This prompted me to read up on related literature where I first came across the subject of living-related renal recipients and their experiences. As part of clinical course requirements, it was necessary to complete a literature review and as part of the subject of this work, I decided to concentrate on the area of living-related renal recipients. I noticed a lack of research specifically regarding the experiences of recipients who had not accessed psychology services. The idea for the research arose from this literature review, as well as my own experiences of working with those preparing for transplant.

In the preliminary stages of planning and becoming familiar with the literature, I was aware that the current research focused on those receiving dialysis or on recipients of a cadaveric renal transplant. Literature regarding living-related transplant tended to focus upon fragmented experiences such as anxiety, depression and quality of life. Although this research has merit, I felt that the experiences of living-related recipients from their own perspectives were missing. This, combined with my interest in the subject, confirmed my final decision to explore recipients' experiences of living-related renal transplant.

During planning, I discussed my idea with two clinical psychologists who had experience of working within the renal field, the head of the renal unit, a professor of surgery, a renal research nurse and two living-related transplant co-ordinators. They were supportive of the concept and offered suggestions regarding methodology as well as practical recommendations. Discussions with staff at the renal unit highlighted a lack of contact between renal and psychology services. Substantive research is conducted within the renal unit, though this is rarely psychological. Staff reported that psychological research would be welcomed, and expressed a keen interest in assisting in the organisational implementation, as well as learning of the findings.

3. Qualitative methodology

In terms of choosing a methodology, I started with the research question (Silvermann, 2000) and it was decided that a qualitative approach was the most appropriate. At this stage, I did not have a preference for methodology, however, in

terms of writing up academic work, I was more familiar with quantitative methods. I welcomed the opportunity to learn more about qualitative strategies.

Following the decision to use a qualitative method, I selected to use an interview design using a self-selecting sample. An interview design was appropriate as this means of obtaining participants' accounts provided a relatively safe environment in which experiences could be discussed. The use of a semi-structured interview schedule allowed relevant topics to emerge (Smith *et al.*, 1995). A self-selecting sample, that is 'a sample selected for study on the basis of their own action in arriving at the sampling point' (Coolican, 1994, p. 45), was suitable as it allowed potential participants to volunteer to take part in the research, without any perceived pressure to do so (Silverman, 2000).

Interpretative phenomenological analysis (IPA) provided the opportunity for recipients to share their experiences of living-related transplantation. The types of experiences offered were unique in the sense that the procedure they underwent is not common, and that each recipient will have experienced transplantation differently due to the reason for their kidney failure, beliefs about their kidney difficulties and varying personal background histories, all of which will have shaped the interpretation of the experience. Recipients also offered a range of times since their transplant, allowing for the effects of time and processing of the experience to be considered. They were also able to compare living-related transplantation and dialysis, a useful contrast to contribute to the research regarding the impact of dialysis. Participants had no experience of any other forms of transplantation, with which to compare their own. Neither did they have experience of the loss of a

transplanted kidney. This and the impact of a retrospective design will have limited the findings.

Delayed reports are likely to be less complete and more likely to contain rationalisations of the experiences which occurred (Gilhooly & Green, 1996). In a retrospective study, data can be unreliable due to recall problems (Bijleveld *et al.*, 1998). Bijleveld *et al.* (1998) suggests three reasons for this including memory loss whereby the respondent cannot remember events, and retrieval problems when the participant has not completely forgotten the events but may have trouble recalling them. Thirdly, participants tend to interpret and re-interpret events, opinions and feelings so that they fit in with their current perception of their lives, called the modification of fit coherent scheme.

A prospective design would have sought to determine the association between a hypothesised factor such as anxiety, and the occurrence of illness, i.e. kidney failure by sampling both exposed and unexposed participants, and then following them for the period of study (Coolican, 1994). This would have required a larger number of participants and an extended period of time in which to collect and analyse the data. Therefore, due to time constraints, this study design was not feasible. The most useful reports are straightforward verbalisations of ongoing thought as it happens (Gilhooly & Green, 1996). However, the design would not have been feasible for this project due to the amount of time and intrusion to participants required to interview continually from diagnosis to one year post-transplant (as determined by study criteria).

I reviewed different qualitative approaches when deciding upon the most appropriate to the study, including content analysis, grounded theory and IPA. Content analysis emphasises the frequency of different types of category e.g. words and phrases (Krippendorff, 1980). However, it fails to interpret findings, instead producing information regarding the relationships between categories. Grounded theory method (Glaser & Strauss, 1967) aims to collect data in order to develop a theory, using inductive strategies for analysing data (Charmaz, 1995). IPA, however, allows the researcher to begin exploration without a predetermined set of ideas about the nature of an experience (Smith *et al.*, 1999). Grounded theory and content analysis do not consider experience within a cultural context, unlike IPA, which places emphasis on the contextual factors within an individual's life which may play a part in the meaning-making of the process (Bruner, 1990). IPA also acknowledges the role of the researcher in the research process to a greater extent than either grounded theory or content analysis (Smith *et al.*, 1999). Indeed, the focus of IPA is on meanings constructed by a person about their situation and world, rather than attempting to understand the event itself (Smith, 2004). For these reasons, IPA seemed the best suited qualitative approach for the examination of recipients' experiences. IPA also appealed due the application of its findings to clinical practice.

I felt keen, although a little apprehensive to conduct qualitative research as my previous research experiences had been in quantitative methodology. However, supervisory experience of IPA and the support of a qualitative research group helped to develop my confidence in using the design. The disadvantage of using IPA was that I was the sole researcher within my year group using the methodology

and therefore there was a lack of fellow trainees with whom to discuss analysis in great detail.

4. Epistemological stance

There are a number of epistemological stances within which the IPA researcher can work (Madill *et al.*, 2000). These have been broadly identified as realist (naïve, scientific or critical), contextual constructionist and radical constructionist (Madill *et al.*, 2000). IPA has an open epistemological stance, but suits a critical realist position (Madill *et al.*, 2000). This provides a balance between realist and social constructionist positions, acknowledging the interaction between participant and researcher. I have found the concept of epistemology challenging to understand. Although I feel more confident in my stance having conducted this research, I continue to feel that there is more that I would like to learn in order to gain a clearer understanding of epistemologies.

5. Conducting the research

The way in which the research was conducted was due to a number of reasons. Firstly, I wanted to make taking part in the research straightforward for participants, to encourage them to participate. I considered that seeing participants on the day of their outpatient appointment would be easier than being visited at home, or arranging an alternative date for the interview which would require a second visit to the hospital. Secondly, reasons for conducting the research as described in section B, 2.0 Method, were due to practical reasons such as time restrictions and

availability of participants. For example, eight participants took part in the study, as eight people opted in to the study. More letters of invitation could have been sent out, but due to time restrictions at this point, there was inadequate time for responses, interviews, transcription and analysis. This therefore prevented potential participants from being invited to take part. Thirdly, the study was conducted in accordance with ethical committee requirements. It was necessary for a member of the renal staff, approved by the committee, to provide potential recipients with information regarding the study and an opt-in slip. Due to patient confidentiality, I was unable to access patient information until a participant opted-in to the study. Making the research appealing, practical reasons and ethical committee suggestions all shaped the way in which the research was conducted.

5.1 Ethical approval

Conducting the research began by gaining ethical approval. This was a novel experience for me. As I was unfamiliar with the renal unit, I was dependent on staff to provide me with information such as how annual review appointments are arranged and appropriate locations to interview. There was a change in the head of the renal unit shortly before submission to the ethical committee. His approval for the study was required and any necessary paper work altered to accommodate this change. This delayed approval from the ethical committee which was obtained in February 2006.

5.2 Recruitment of participants

Due to ethical restrictions, I was unable to access patient information until participants had opted-in to the study. I was therefore dependent on a transplant co-ordinator to identify patients who satisfied the criteria for the study and were attending annual review on dates suitable for interviews to take place. This was time consuming and recruitment would not have been possible without the co-ordinator's assistance, for which I am grateful. Recipients were given three weeks to consider their interest and subsequent involvement in the research. The set time required between inviting potential participants, and the date in which they could be interviewed, was made in agreement with the ethical committee. This, combined with the delay in obtaining ethical approval, created a degree of stress. I was concerned that a lack of interest from participants could delay interviewing and subsequent analysis and write-up. To my relief, eight participants volunteered, preventing any delays.

Letters of invite to take part in the study, written by the professor of the head of the renal unit, a professor of surgery, and a participant information sheet, were sent to potential recipients. I considered that offering the opportunity for interview on the same day as annual review would encourage recipients to take part, due to convenience. Ethical requirements dictated that the letter of invite be written by the professor of surgery. He had performed all living-related recipients' surgeries to date, and therefore all invited recipients had had personal contact with him. This may provide explanation as to the ease of recruitment. Once an opt-in slip had been returned, I contacted recipients via telephone to arrange a time to discuss the

research further. This personal contact may have allowed potential participants to make an initial judgement as to whether they considered I would be someone they would like to talk to about their experiences.

5.3 Interviewing

Prior to interviewing, I had been warned that room space within the outpatient clinic where annual review appointments took place may be problematic. This proved to be the case. However, the transplant co-ordinator kindly offered the use of her room for interviewing. A sign was placed on the door informing people that interviews were taking place, asking not to be disturbed. During a few of the interviews, however, members of staff did enter the room. This had a temporary effect on the flow of interviews which recommenced shortly afterwards.

Participants were met in the waiting area of the outpatient clinic, and were walked to the location of the interview. The five minute walk allowed for an initial rapport to be created. It may have served to relax participants prior to discussing personal experiences. However, participants were keen to discuss their transplant during this time. I attempted to divert conversation, as it was felt that any prior discussion of interview topics may influence participants' accounts.

I was genuinely interested in participants' experiences, and I hope that this was conveyed during the interviews, and served to encourage them to share information. The amount and ease in which participants spoke, varied. Some were eager to share stories and provided much detail with little questioning required. Others required more prompting and tended to give brief answers. Attempts to encourage

elaboration using non-verbal indicators such as nodding, asking for more information or using pre-determined prompts were not always successful. Participants' lack of expansion may be a result of the previous medical appointment whereby they may have been asked specific questions in a short period of time, and required to answer succinctly. The opportunity to elaborate on questions or receive prolonged focused attention for sixty minutes may have been unexpected and unusual. These participants may have difficulty expressing themselves. I tended to ask too many questions, some of which were leading, perhaps done in an attempt to encourage these participants to talk, or expand further. This was due to my anxiety at wanting to have asked all the questions, as well as having difficulty in encouraging participants to expand. It did not allow participants to provide further details, and on some occasions, may have cut short their answers. Having reflected on this and read through the transcripts, I made a conscious effort to talk a lot less and ask fewer open questions during future interviews, thus allowing participants to talk more. This is evident when comparing interview transcripts one and two, to those subsequent.

Interviews with participants who struggled to expand, or those I allowed less opportunity to expand, tended to be shorter in length. I became aware that I was repeating questions, partly in the hope that participants might answer differently and provide richer data, and also to fulfil the time allocation of sixty minutes. This sometimes felt futile, and therefore when I considered participants were repeating themselves, and I had asked all questions, interviews were ended despite falling short of the allocated time. Participants were asked if they would like to add anything else, providing opportunity to mention topics that had not been previously

covered. I assumed incorrectly that shorter transcripts, or those belonging to participants who had difficulty elaborating, were going to be restrictive in terms of interpretation. However, upon analysis, all transcripts were unexpectedly equally rich.

Reflective listening skills during interviews, reflecting back and summarising participants' responses, can be used to check the researcher's understanding of the participant's meaning (Stiles, 1993). It enables the researcher to gain an insider perspective (Mason, 1993). However, at times, I felt that I may have expanded too far upon participants' reflections, making assumptions which may have been falsely agreed with by participants, or resulting in them defending or reiterating their point unnecessarily. I became aware of this and the possible impact on interviews and subsequent findings, and made efforts to stop doing so in subsequent interviews.

When gaining consent from participants, they were informed that a secretary would transcribe interviews. I had planned on transcribing three of the interviews, however due to time constraints following the delay in ethical approval, I felt that I could use the time it would have taken to transcribe more constructively. I read through each transcript whilst listening to the interview on audio tape twice, in order to become familiar with the data.

Immersing myself in the data was challenging due to the simultaneous demands of clinical placements, as well as continually writing sections of the report. At these times, I felt stressed at juggling the range of tasks which needed to be carried out concurrently. I managed these demands by creating timetables, breaking each task

down into more manageable and organised sections, allocating a date for which each would be carried out and completed. This made the research feel more manageable, and achievable. On completion of each small section, the feeling of satisfaction (and a small reward!) motivated me to continue with each subsequent task.

6. Analysis and writing up

Analysis of the data was an interesting process. During interviews, I noted similarities in participants' accounts. I therefore felt very keen to code transcripts and identify themes to validate my suspicions. I found it interesting that some themes which arose from analysis were unexpected as I had not been aware of them during the interviews. I felt impatient at the lengthy analytic process as I was keen to complete analysis and see what I had found. The satisfaction at completing the coding of each transcript provided me a small sense of achievement, helping me to feel the final results were impending, and reducing my impatience.

The constant revision of the master theme list was an extensive process, which was sometimes frustrating. At times, a neat, clear set of super-ordinate themes and corresponding sub-ordinate themes had been developed. This had taken significant time to compose and had to be revised following the analysis of a further transcript. This was disheartening, and enhanced my impatience to assemble the final findings.

I found myself relying perhaps too heavily on guidelines and instructions for carrying out IPA, particularly Smith (1999). Although much time was spent reading

and learning how to use the method prior to analysis, I felt the need to ensure that each stage of the analysis was being completed according to recommendations, due to my anxiety at being a novice qualitative researcher. As coding commenced, I began to feel more confident, having increased faith in my interpretations of data.

My awareness of theories will undoubtedly have impacted on the coding and analysis of data. Although I have an interest in health psychology, it is important for me to recognise that as a relative novice in the area, I have limited knowledge of health psychology theories. Despite becoming more familiar with the literature during the process of research, the analysis and interpretation of results will have been limited due to my lack of knowledge. My beliefs and assumptions will also have been played out in the interpretation of the data, and have contributed to the construction of meanings (Elliott *et al.*, 1999). Increased knowledge and awareness of theory may have shaped the interview schedule differently and therefore produced alternative findings. Subsequent analysis and interpretation would also have yielded different results, potentially more informed by, or interpreted with, the use of theories.

Integration and consideration of theories such as the health belief model (Rosenstock, 1966), self-regulatory model of illness (Leventhal *et al.*, 1989) and attribution theory (Weiner *et al.*, 1972) could have improved the quality of the evidence by providing frameworks in which to consider and inform the findings. For example, reference to the health belief model (Rosenstock, 1966) may have enhanced understanding of the ways in which recipients perceive and make sense of their susceptibility and severity of kidney failure, and the benefits of the transplant.

Similarly, consideration of a self-regulatory model of coping with illness (Leventhal *et al.*, 1989) could have explained motivation and reasons for transplantation.

Attribution theory (Weiner *et al.*, 1972) would have explored illness cognitions experienced by recipients. Consideration of these theories, and others, may have improved the quality of the findings produced.

The findings can inform current psychological thinking in a number of ways. The research has elicited some original findings, such as the presence and impact of shock during diagnosis, and the identification of anticipation pre-transplant. These results can contribute new ideas to existing research which can be considered in the development of models aimed at understanding recipients' experiences. Secondly, the data produced have replicated the findings of existing research, e.g. the kidney regarded as a gift (Sque *et al.*, 2006) and anxiety about the donor's future health (Fukunishi *et al.*, 2002). This re-iteration of findings provides some confirmation of the validity of existing studies (Coolican, 1994). Thirdly, the findings may elucidate research questions for future studies, which could subsequently inform future psychological thinking.

A challenge of writing up the research was the restriction of the word limit, especially as quotations were included within the word count. I found it useful to write the results in their full capacity in order to aid my own understanding. Subsequently I had to cut out substantial amounts of text, which was a testing process, but offered practise for the preparation for publication. I intend to publish the study in peer reviewed and academic journals. It is important that research has

clinical implications, and I hope to share findings of the present study with members of the renal unit in which it was conducted.

7. Enhancing methodological rigour and quality criterion

Traditional quantitative criteria for evaluating research quality, such as reliability, are based on the assumptions of researcher objectivity and disengagement from the analytic process, and are not wholly applicable to qualitative research (Madill *et al.*, 2000). Guidelines for the publication of qualitative research, encouraging its rigour, have been developed (Barbour, 2001; Elliott *et al.*, 1999). These were adhered to in order to determine that IPA had been carried out as rigorously as possible.

Providing credibility checks is suggested as a valuable means of auditing that the analysis is sufficiently grounded in the data (Smith, 2004). In order to do this, small sections of transcript were coded by members of the qualitative research group. Although I was the sole researcher using IPA, the facilitator of the group had experience of the methodology, and instructed members of the group on how to code using the methodology. Checking back (respondent validation) with participants to assess the credibility and reliability of the interpretation, as recommended by Elliott *et al.* (1999), was not carried out. This was due to time constraints and I considered it might corrupt rather than enrich the data, as suggested by Barbour (2001).

Internal coherence is described as the need to concentrate on whether the argument presented by the research is internally consistent and justified by the data. Smith

(2003) recommends that verbatim evidence, i.e. participants' excerpts, be included in the write up of the study, allowing readers to validate internal coherence. I selected excerpts which I hope adequately allow for this, and also illustrate the analytic process, enabling interpretation and inference to be open to scrutiny by the reader. Grounding the interpretation in examples, as was done, is considered a means of ensuring methodological rigour and quality criterion (Elliott *et al.*, 1999).

As well as taking the above steps to ensure IPA had been carried out as rigorously as possible, recommendations made by Lincoln and Guba (1985) were followed. This includes the availability of an audit trail so that another researcher can check the process of analysis. The use of a reflexive diary and a record of master theme lists were kept in accordance with these recommendations. The extent to which researcher reflexivity is built into the process is also viewed as a method of assessing methodological rigour (Lincoln & Guba, 1985). This issue is addressed below under the heading 'Reflexivity'.

Strengths of the study from a methods point of view include the rigorous carrying out of IPA, using the above quality criterion. An asset of IPA is its ability to reveal unanticipated phenomena (Shaw, 2001). Rather than embarking on a project with a pre-conceived set of hypotheses to confirm or refute, the methods of data collection used in conjunction with IPA are flexible and open-ended allowing participants to discuss aspects of their experience which the researcher does not expect (Shaw, 2001). The strength of IPA is that researchers are able to investigate phenomena from a new perspective by learning from those who are experiencing it, rather than from existing studies which may be dated. As in this study, previously undiscovered

constructs can be identified due to this method of investigation. New findings, including those of current study, immediately become contemporary and therefore relevant to individuals' current lived experience. Another strength of this study from a methodological perspective is its, and IPA's capacity to investigate human experience within a cultural context (Bruner, 1990). The study places emphasis on contextual factors that are at work within an individual's life which may directly or indirectly play a part in the meaning-making process (Bruner, 1990). The implications of this are that IPA, and the current study can reveal and deal with the idiosyncrasies of individuals' experiences and the elements that are shared by others (Shaw, 2001). Across a sample of participants, the results of a project using IPA such as this, will reflect both these subjective, unshared aspects of the experience which are integrated to form a series of accounts which tell a comprehensive story of the subject being investigated (Reason & Rowan, 1981).

Despite these strengths of the research, some methodological limitations exist. The most cited criticisms of IPA are the presumed lack of reliability and validity. Although measures were taken to enhance quality criterion, the ability to replicate observations (reliability) and to obtain accurate impressions of the study (validity) (Kirk & Miller, 1986) could not fully be implemented. It was not possible to replicate the study due to time constraints. Additionally, this would have needed to be carried out by another researcher to ensure maximum reliability, which was not feasible at this time. The validity of the study could have been tested by checking the findings with the participants, but again due to time constraints, this was not possible. A larger sample size is often used to seek common themes and patterns in order to ensure validity (Maxwell, 1992). The use of eight participants in this study,

however, is considered average within IPA approach (Schaffir & Stebbins, 1991). Some researchers may use triangulation, i.e. the use of different strategies to approach the same topic of investigation (Miles & Huberman, 1984). The use of a questionnaire measuring anxiety such as the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1989) may have enhanced the validity of the findings.

Another limitation of the study was the researcher's inability to observe all factors that might influence the situation under study (Schaffir & Stebbins, 1991) such as time restrictions and financial constraints. With regard to this study, the limitation of the number of participants may have restricted my ability to review a range of individuals undergoing transplantation. Purposive sampling may have allowed for the selection of a variety of participants, however, this is a more commonly used technique in grounded theory (Maxwell, 1992).

8. Reflexivity

Qualitative methods are often criticised for the interpretative role played by the researcher (Greenhalgh & Taylor, 1997). The process of reflexivity allows for the acknowledgement of this role (Elliott *et al.*, 1999). It requires an awareness of the researcher's contribution to the construction of meanings throughout the research process, and an acknowledgement that it is not possible to remain outside of the subject matter whilst conducting the study.

My position is that of a white, British, middle class, trainee clinical psychologist. Working currently in an oncology setting, and previously as an assistant

psychologist within a medical psychology setting, I have developed preconceptions with regards to what it is like to experience a chronic illness. These include an expectation of a range of emotional responses to diagnosis and prognosis, exhaustion at undergoing constant treatments, such as dialysis or chemotherapy, and the anticipation and desire to recover. Personal experiences of illness within my family, and a friend currently undergoing preparation for a living-related kidney transplant, have undoubtedly shaped my beliefs regarding the experiences of illness and will have impacted on my interpretation of the data. Throughout analysis, I was mindful of the potential influence of personal material, but tried to put this aside in favour of participants' experiences of living-related transplantation. Awareness of my position has helped me to recognise my own assumptions, beliefs and interests which are played in my interpretation of the data, and has facilitated consideration of how my personal perspectives may have influenced the research.

9. Learning points

As a result of conducting this research, I feel I have:

- Developed confidence at conducting short, time-limited, clinically relevant research.
- Developed skills for submitting a successful proposal to a Research and Ethical Committee.

- Learnt how to competently critique psychological literature and identify discrepancies. I have also learnt to effectively critique my own research.
- An awareness of the requirements of successful research including, but not exhaustively: organisational and time management skills, the ability to write stylistically and maintaining motivation.
- Achieved advanced understanding of the literature regarding living-related renal transplantation.
- Gained knowledge and deeper understanding of qualitative methodologies, conducting interviews, and analysing data using IPA methodology. I would therefore feel confident at conducting qualitative research in the future.
- Increased my awareness of the variety and ranges of individual experience.

The list is not exhaustive, and I hope that the skills I have developed and enhanced whilst conducting the study will continue to improve and expand throughout my future career as a clinical psychologist.

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Section D

Appendices

Appendix A. Notes for contributors, British Journal of Health Psychology

The aim of the British Journal of Health Psychology is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology across the life span, ranging from experimental and clinical research on aetiology and the management of acute and chronic illness, responses to ill-health, screening and medical procedures, to research on health behaviour and psychological aspects of prevention. Research carried out at the individual, group and community levels is welcome, and submissions concerning clinical applications and interventions are particularly encouraged.

The following types of paper are invited:

- papers reporting original empirical investigations;
- theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;
- review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology;
- methodological papers dealing with methodological issues of particular relevance to health psychology.

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 5,000 words, although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Reviewing

The journal operates a policy of anonymous peer review. Papers will normally be scrutinised and commented on by at least two independent expert referees (in addition to the Editor) although the Editor may process a paper at his or her discretion. The referees will not be aware of the identity of the author. All information about authorship including personal acknowledgements and institutional affiliations should be confined to the title page (and the text should be free of such clues as identifiable self-citations e.g. 'In our earlier work...').

4. Online submission process

1) All manuscripts must be submitted online at <http://bjhp.edmgr.com>.

First-time users: click the REGISTER button from the menu and

enter in your details as instructed. On successful registration, an email will be sent informing you of your user name and password. Please keep this email for future reference and proceed to LOGIN. (You do not need to re-register if your status changes e.g. author, reviewer or editor).

Registered users: click the LOGIN button from the menu and enter your user name and password for immediate access. Click 'Author Login'.

2) Follow the step-by-step instructions to submit your manuscript.

3) The submission must include the following as separate files:

- Title page consisting of manuscript title, authors' full names and affiliations, name and address for corresponding author - [Editorial Manager Title Page for Manuscript Submission](#)
- Abstract
- Full manuscript omitting authors' names and affiliations. Figures and tables can be attached separately if necessary.

4) If you require further help in submitting your manuscript, please consult the Tutorial for Authors - [!\[\]\(dc868d63894410998f1f9e1f6456fecb_img.jpg\) Editorial Manager - Tutorial for Authors](#)
Authors can log on at any time to check the status of the manuscript.

5. Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.
- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate page. The resolution of digital images must be at least 300 dpi.
- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions - [!\[\]\(f7476af7c6ee781273c9cca097bac596_img.jpg\) British Journal of Health Psychology - Structured Abstracts Information](#)
- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full.
- SI units must be used for all measurements, rounded off to practical values if appropriate, with the Imperial equivalent in parentheses.
- In normal circumstances, effect size should be incorporated.

- Authors are requested to avoid the use of sexist language.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations etc for which they do not own copyright.

For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association, Washington DC, USA (<http://www.apastyle.org>).

6. Publication ethics

Code of Conduct -  [Code of Conduct, Ethical Principles and Guidelines](#)
Principles of Publishing -  [Principle of Publishing](#)

7. Supplementary data

Supplementary data too extensive for publication may be deposited with the British Library Document Supply Centre. Such material includes numerical data, computer programs, fuller details of case studies and experimental techniques. The material should be submitted to the Editor together with the article, for simultaneous refereeing.

8. Post acceptance

PDF page proofs are sent to authors via email for correction of print but not for rewriting or the introduction of new material. Authors will be provided with a PDF file of their article prior to publication for easy and cost-effective dissemination to colleagues.

9. Copyright

To protect authors and journals against unauthorised reproduction of articles, The British Psychological Society requires copyright to be assigned to itself as publisher, on the express condition that authors may use their own material at any time without permission. On acceptance of a paper submitted to a journal, authors will be requested to sign an appropriate assignment of copyright form.

10. Checklist of requirements

- Abstract (100-200 words)
- Title page (include title, authors' names, affiliations)
- Full article text (double-spaced with numbered pages and anonymised)
- References (APA style). Authors are responsible for bibliographic accuracy and must check every reference in the manuscript and proofread again in the page proofs.

Appendix B. Details of papers included in the literature review

Authors	Date	Variables measured	Instruments	Stage of illness		Country	Sample size
					Haemodialysis/Transplant		
Adler	1972	Coping mechanisms	Observation	✓		USA	1
Akman <i>et al.</i>	2004	Depression	Beck Depression Inventory	✓	✓	Turkey	88
Auer <i>et al.</i>	1990	Age, risk factors, illness	SF-36, author questionnaire	✓		Sweden	26
Baines & Jindal	2003	Anxiety	BAI	✓	✓	UK	31
Baines <i>et al.</i>	2002	Emotional state	BDI, semi-structured interview		✓	UK	49
Balinsky	2000	Incidence	Survey of incidence	✓		UK	71
Benedetti <i>et al.</i>	1994	Age	Survey of graft survival		✓	USA	47
Binik <i>et al.</i>	1990	Marital role, illness	Survey of marital and illness status	✓		Canada	89
Burton <i>et al.</i>	1998	Support	Author questionnaire	✓		Canada	412
Bryan <i>et al.</i>	1998	Health related quality of life	SF-36, EuroQol EQ-5D		✓(liver)	UK	147
Cameron <i>et al.</i>	2000	Quality of life	WHOQOL-BREF-TAIWAN	✓	✓	Taiwan	240
Carver <i>et al.</i>	1993	Coping	Author questionnaire		breast cancer patients	USA	38

Authors	Date	Variables measured	Instruments	Stage of illness		Country	Sample size
					Haemodialysis/Transplant		
Christensen & Elhers	2002	Psychological distress, coping	COPE	✓		USA	63
Christensen <i>et al.</i>	1994	Information vigilance, coping	Survey of medical records	✓		USA	149
Christensen <i>et al.</i>	1990	Medical adherence	Survey of medical records	✓		USA	72
Conrad & Murray	1999	Recipient and donor views	Systematic literature review	✓	✓	USA	undefined
Coresch <i>et al.</i>	2003	Prevalence of ESRF	Survey	✓		UK	15,625
Craven <i>et al.</i>	1987	Depression	Diagnostic interview schedule	✓		UK	99
DeGeest & Moons	2000	Quality of life assessments	Literature review		✓	Belgium	undefined
Devins <i>et al.</i>	1982	Self-efficacy, mood	Author questionnaire	✓		USA	52
Dubovsky & Penn	1980	Anxiety, depression	Observation		✓	USA	1
Fallon <i>et al.</i>	1997	Stress, quality of life	KTRSS	✓		UK	30
Finkelstein & Finkelstein	2000	Depression	KdQofL, SF-36	✓		USA	130
Forsberg <i>et al.</i>	1999	Pain, health related quality of life	HAD, SF-36, POM		✓	Sweden	76

Authors	Date	Variables measured	Instruments	Stage of illness		Country	Sample size
				Haemodialysis/Transplant			
Frank <i>et al.</i>	2003	Quality of life	SF-36, Pafrey's health questionnaire	✓	✓	Israel	72
Frazier <i>et al.</i>	1994	Non-compliance	BDI, BSI, ISSB, CSI		✓	USA	241
Frey	1990	Stress	KTRSS		✓	USA	48
Gibson	1996	Attitudes	Literature Review	kidney donors		UK	undefined
Grassi <i>et al.</i>	1993	Stress, quality of life	undefined	cancer patients		Italy	34
Griva <i>et al.</i>	2002	Quality of life, emotional responses	SF-36, TEQ		✓	UK	347
Hagberg	1974	Coping	undefined		✓	USA	26
Hathaway <i>et al.</i>	1998	Quality of life	3 QoL questionnaires (undefined)		✓	USA	91
Heck <i>et al.</i>	2004	Depression, anxiety	semi-structured interviews		✓	Germany	31
Hellgren <i>et al.</i>	1994	Health quality of life	Author questionnaire	✓		Sweden	120
Hestin <i>et al.</i>	1994	Age	Survey		✓	Greece	23
House	1987	Social functioning, mood	Interviews	✓	✓	UK	80
Iacovides <i>et al.</i>	2002	Age, life satisfaction, sexual functioning	ZDRS, LSI, LSFS	✓		Italy	87

Authors	Date	Variables measured	Instruments	Stage of illness		Country	Sample size
				Haemodialysis/Transplant			
Idelson <i>et al.</i>	1974	Self-concept	Observation	Heart attack patients		USA	12
Jofre <i>et al.</i>	1998	Quality of life	KS, SIP		✓	Spain	93
Kaplan De Nour <i>et al.</i>	1968	Emotional reactions	Defense mechanisms		✓	Israel	9
Keogh & Frehally	1999	Adjustment and acceptance	FAIS		✓	UK	273
Kimmel	2001	Depression	BDI		✓	USA	56
Kimmel	2002	Depression	Undefined		✓	USA	23
Kimmel <i>et al.</i>	1998	Psychiatric illness	Survey		✓	USA	45
Kimmel <i>et al.</i>	1993	Depression	Survey		✓	USA	34
Krause & Stryker	1984	Stress and well-being	Undefined	General population		USA	Undefined
Kutner <i>et al.</i>	1985	Depression, anxiety	ZSRDS, TES, SDRS		✓	USA	48
Lev & Owen	1998	Adjustment	SFR		✓	USA	65
Lindquist <i>et al.</i>	1998	Coping, quality of life	Undefined		✓	Sweden	22

Authors	Date	Variables measured	Instruments	Stage of illness		Country	Sample size
				Haemodialysis/Transplant			
Martin & Thompson	2000	Quality of life	HAD, LCB, KDQOL		✓	UK	56
Martin-McDonald	2003	Dependency on dialysis	Interviews	✓		Australia	10
Mittal <i>et al.</i>	2001	Quality of life	MCS, SF-36	✓		USA	15
Merkus <i>et al.</i>	1999	Physical symptoms, dialysis	SF-36	✓		Netherlands	226
Molzahn	1991	Quality of life	Semi-structured interviews	✓		USA	10
Murray <i>et al.</i>	1999	Perceptions of kidney transplant	Author questionnaire	✓		USA	115
Newell	1991	Body image	Observation	General population		UK	Undefined
Niu & Li	2005	Quality of life	WHOQOL-BREF-TAIWAN	✓	✓	Taiwan	240
Oldenberg <i>et al.</i>	1988	Quality of life	Semi-structured interviews	✓		Australia	102
Patel <i>et al.</i>	2005	Social support	Literature Review	✓		USA	Undefined
Porter & Stone	1995	Coping	Author questionnaire	General population		USA	156
Ptacek <i>et al.</i>	1992	Gender, appraisal, coping	Author questionnaire	College students		USA	186

Authors	Date	Variables measured	Instruments	Stage of illness		Country	Sample size
				Haemodialysis/Transplant			
Pucheu <i>et al.</i>	2005	Attributions, coping, quality of life	KDQOL, MOSSF36, WCCL	✓		France	47
Reynolds <i>et al.</i>	1993	Adjustment	Undefined measure	✓	✓	UK	32
Robello <i>et al.</i>	2001	Quality of life, age	Author designed questionnaire	✓	✓	Spain	31
Rocco <i>et al.</i>	1997	Quality of life, diet	QWB, SCL-90R	✓	✓	USA	1,284
Rocha <i>et al.</i>	2001	Depression	BDI		✓	Brazil	64
Sanner	2003	Conceptions of transplantation	Interviews		✓	Sweden	35
Schnuelle <i>et al.</i>	1998	Survival	Survey using medical records		✓	Germany	309
Schover	1991	Sexuality, body image, relationships	Literature review		✓	USA	Undefined
Short & Wilson	1969	Denial	Observation	✓		USA	5
Simmons <i>et al.</i>	1971	Stress	Interviews	✓		USA	6
Srivastava	1988	Coping strategies	JCS, SWED-QUAL	✓		USA	55
Symister & Friend	2003	Social support, depression, self esteem	Author questionnaire	Chronic illness		USA	86
Tanriverdi <i>et al.</i>	2004	Quality of life, mood	BDI, BAI, SF-36		✓	Turkey	49

Authors	Date	Variables measured	Instruments	Stage of illness	Country	Sample size
				Haemodialysis/Transplant		
Tsay & Healstead	2002	Self-efficacy, depression, quality of life	Empowerment programme	✓	Taiwan	50
Vamos	1997	grief reactions	Interview	✓	Australia	2
Watson <i>et al.</i>	1991	Emotional control, adjustment, depression	HAD, MAC	✓	UK	44
Weizer <i>et al.</i>	1989	Suicide	Psychiatric assessment	Donors	Israel	2
White <i>et al.</i>	1990	Stress, coping, quality of life	SF-36, KTSS	✓	USA	32
Wright <i>et al.</i>	1999	Adjustment	Interview	✓	UK	17
Zeiner	1995	Stress	Undefined	Students	Israel	241

Appendix C. Ethical committee approval correspondence



‘A County Research Ethics Committee’

Address
(removed for anonymity)

06 February 2006
Reissued 09 February 2006

Miss Anna L. Symonds
Trainee Clinical Psychologist
(Address removed for anonymity)

Dear Miss Symonds,

Full title of study: **The experiences of patients who have received a kidney from a living-related donor**
REC reference number: **05/Q2502/149**

Thank you for your letter of 12 January 2006, responding to the Committee’s request for further information on the above research and submitting revised documentation.

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

Confirmation of ethical opinion

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

Ethical review of research sites

The favourable opinion applies to the research sites listed on the attached form. Confirmation of approval for other sites listed in the application will be issued as soon as local assessors have confirmed they have no objection.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

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

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application	1	25 November 2005
Investigator CV	V1 9.9.05	09 September 2005
Protocol	V1 9.9.05 (last saved 25.11.05)	09 September 2005
Covering Letter		09 September 2005
Peer Review	19.08.05	19 August 2005
Letter of Invitation to Participant	V1 15.11.05 (with reply slip)	15 November 2005
Participant Information Sheet	V2	12 January 2006
Participant Consent Form	V2	12 January 2006
Response to Request for Further Information		12 January 2006
Supervisor CV	V1 9.9.05 (Noelle Robertson)	09 September 2005
Letter of Permission from UHL (Professor Michael Nicholson)	29.07.05	09 September 2005
Flowchart	V1 9.9.05	09 September 2005
Interview Questions	V1 9.9.05	09 September 2005

Research governance approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final research governance approval from the R&D Department for the relevant NHS care organisation.

Statement of compliance

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

05/Q2502/149

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

Chair
(Name of Trust) Local Research Ethics Committee

Appendix D. Letter of invite



'An NHS Trust'
Address
(removed for anonymity)

Date

Dear Sir/Madam,

Re: Finding out about the experiences of patients who have received a kidney from a living-related donor

A research study is being carried out at (removed for anonymity) by Anna Symonds, Trainee Clinical Psychologist.

The study has been designed to gain a greater understanding of what it is like to receive a kidney from someone you're related to. We are interested in hearing about your opinions and experiences, and would welcome any input you may be able to give us. By doing this, we hope to learn about what it is like to receive a kidney, and to see if psychological support may be useful to those receiving a kidney in the future.

If you would like to take part in this study, details of which are given in the information sheet enclosed, please complete the reply slip enclosed with this letter, and return it in the pre-paid envelope. The investigator will then contact you to arrange a convenient time to obtain your consent, and ask you to take part in an interview, which should last approximately sixty minutes. If possible, the interview may take place on the day of your annual review.

I would like to thank you for taking time to read this letter and hope to hear from you soon. If you have any queries, please feel free to contact me, or Anna Symonds on the telephone numbers provided on the information sheet.

Yours faithfully

(name removed for anonymity)
Professor of Surgery

Encs.

Dear Researcher,

I am interested in taking part in the research as described in the patient information sheet that was sent to me. I understand that by giving my details, I will be contacted by a member of the research team. I understand that I can withdraw from the research at any time without any affect to the quality of my care, or that of my donor.

My name: _____

My address: _____

My telephone number: _____

Please return this form in the stamped addressed envelope provided as soon as possible. Thank you.

Appendix E. Participant information sheet



School of Psychology – Clinical Section

(details removed for anonymity)

12th January 2006

Dear Participants,

Finding out about the experiences of patients who have received a kidney from a living-related donor

You are being invited to take part in a research study. Before you decide if you would like to take part, 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?

Our project aims to gain a greater understanding of what it is like to receive a kidney from someone you are related to. We are interested in hearing about your opinions and experiences, and would welcome any input that you would be able to give us. We want to ask you what it has been like to receive a kidney from a relative, how it may have affected you, and whether your relationship with the donor has changed since receiving the kidney. By doing this, we hope to improve the psychological help available to those who have received a kidney. The research will take place over the course of one year, although your input would involve an interview lasting approximately sixty minutes.

Why have I been chosen?

You have been chosen because you have received a kidney from a living-related donor over twelve months ago. We are contacting all patients who have been identified by the transplant co-ordinator as having received a kidney from a living-related donor over twelve months ago, and who are due for annual review between February and May.

Do I have to take part?

It is important to remember that it is up to you whether or not you take part. If you decide to take part, then you will be asked to sign a 'consent form'. This is so that we have a record which shows that we explained the research to you properly, before you agreed to participate. Signing the consent form does not mean that you cannot change your mind about taking part. If you decide to take part, you are free to withdraw at any time and without giving a reason.

This is a research project and it has no link to the standard of care that you and/or your related donor receive. Whether you decide to take part in the study or not is up to you, and your decision will not affect the treatment that you or your related donor receive.

What will I have to do?

If you decide to take part, you will be asked to meet a female researcher at (removed for anonymity) for sixty minutes. During this time, the researcher will ask you a few questions to enable you to discuss what it has been like receiving a kidney from a relative. The interview will be recorded on a tape recorder so that the research team will have an accurate record of what is said. Only members of the research team will have access to the tapes, and your name, and any other information that may identify you will be erased from the tape.

The researcher will study the tapes and will make detailed notes about what you have said. These notes and tapes will be treated confidentially. Tapes will be destroyed after the research study has ended. In the notes, and in the research reports that will be written about them, we will use what you tell us to think about what it is like to receive a kidney and the ways in which psychologists can improve the help they give to those that receive kidneys from living-related donors. Although your words may be used, your identity will not be revealed. In all of the reports and documentation for the research project, you will be referred to by a false name. Other specific information that may identify you will be altered or removed.

What if I am harmed by taking part in this research project?

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you

may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, normal National Health Service complaints mechanisms would be available to you.

If you have any questions or concerns about this project, please do not hesitate to contact Anna Symonds, Trainee Clinical Psychologist on (removed for anonymity), or (removed for anonymity), Head of Surgery on (removed for anonymity).

Yours sincerely,

Anna Symonds
Principal Investigator
Trainee Clinical Psychologist

Appendix G. Proof of consent training and assessment

Directorate of Research & Development

Nurses and Allied Health Professionals obtaining informed patient consent for clinical research studies

A COMPETENCY-BASED ASSESSMENT TOOL

Name: Anna SYMONDS
 Position: Trainee Clinical Psychologist
 Name of research study for which consent to be taken: The experiences of patients who have received a kidney from a living related donor.
 Principal Investigator (if applicable): Anna SYMONDS

To be completed by the assessor

Assessment	Date	Name of Assessor (print)	Signature of assessor (if competent)
Jan 13 th	06.	SARAH NICHOLSON	SUNICHOL

(use 2nd form if >4 assessments)

Completion Code: pass = ✓; fail = X; not applicable = N/A

		Assessment	1	2	3	4
Communication						
1.	Introduces self to patient/relatives and establishes rapport.		✓			
2.	Ensures that the information-giving and consent-taking process is conducted with as much privacy as possible, and maintaining dignity.		✓			
3.	Ensures that the patient is comfortable during the interview.		✓			
4.	Communicate appropriately, with regards to pace and language.		✓			
5.	Explains procedure in clear and simple terms.		✓			
6.	Makes use of diagrams if appropriate.		N/A			
7.	Encourages the patient to ask questions at any stage of the interview.		✓			

		Assessment	1	2	3	4
The Process						
8.	Makes use of an interpreter (if applicable).		N/A			
9.	Makes an accurate assessment of patient's capacity to consent to the research study.		✓			
10.	For an incompetent adult: Is able to justify decision that patient lacks capacity consent to the research study and therefore		N/A			
11.	For an incompetent adult: Makes reasonable efforts to assist the patient to reach a decision - involves relatives in decision-making process. (if applicable).		N/A			
12.	For an incompetent adult: Is able to justify that enrolment in the research study has potential benefits for the patient.		N/A			

13.	Explains the research study and the treatment /procedures involved (including randomisation if appropriate)	✓			
14.	Explains the potential/intended benefits of the research study treatment/procedure. If there is no intended clinical benefit to the patient at this time, the patient should be made aware of this	✓			
15.	Explains the reasonably foreseeable risks or inconveniences to the patient.	✓			
16.	Explains any extra procedures, which may become necessary during the research study/treatment/procedure (e.g. invasive procedures, taking of blood).	N/A			
17.	Ensure that the patient/parent research information leaflet has been read (use taped version if necessary).	✓			
18.	Explains the type of medication used during the research study / treatment procedure (if applicable).	N/A			

Knowledge		1	2	3	4
19.	Explains alternative procedures or treatments that may be available and their potential benefits and risks (if applicable).	N/A			
20.	Discusses any anticipated payment/expenses for the patient in relation to participation in the research study	N/A			
21.	Ensure the patient is aware of compensation and/or treatment available in the event of a research study related injury	✓			
22.	Gives patient/parent impartial information enabling them to make their own decision to participate in the research study- ensuring that participation in the research study is entirely voluntary and that they may withdraw at any time.	✓			
23.	Is able to answer questions of patient/relatives/parents with clarity and accuracy.	✓			
24.	Seeks advice from senior colleagues if unable to answer questions	✓			
25.	Ensures patient/parent reads and signs the Consent form appropriately	✓			
26.	Asks if patient has Advance Directive/Living Will (e.g. Jehovah's Witness form)	N/A			
27.	Involves <u>child</u> in decision-making process, and invites him/her to sign the form (if appropriate).	N/A			
28.	Consults with the Principal Investigator or a named medically qualified co-investigator who confirms in writing that the patient is appropriate to enter the research study.	N/A			
29.	Is able to demonstrate knowledge and expertise of the procedure, trial medication/treatment, alternative treatments, operation etc for which the patient is consenting.	✓			
30.	Is able to decide what is valid informed consent.	✓			
31.	Shows awareness of the various factors to be taken into account when assessing the "best interests" of patients (i.e. physical, psychological, social, etc.)	✓			
32.	Shows awareness of how to assess competence in a child if parent is unable to consent.	N/A			
33.	Shows awareness of what constitutes a valid Advance Directive.	N/A			
34.	Shows awareness of what to do if patient exercises his/her right to waive Information.	✓			

Appendix H. Semi-structured interview schedule

Introduction

Introductions, background to research, confidentiality, format including tape recording, any initial questions from the participant, consent form.

Background

Age, gender, ethnicity, length of time since transplant, relationship to living donor.

Introduction

I was wondering if I could start by asking you to tell me a little bit about yourself and a brief history of your kidney problem from when it started to when you had the transplant?

The Transplant

I understand that you have received a kidney from a living related donor. I wonder if you could tell me how it came about that you had a living related transplant?

Can you describe to me how it felt to have a transplant?

(Prompt) To what degree did you experience physical difficulties?

(Prompt) Were there any difficulties with the procedure or your recovery?

Did any recipients share their experiences with you prior to your transplant?

To what extent has the transplant affected your daily life?

(Prompt) Has it had any affect on your employment?

(Prompt) Has it affected any other activities?

Have there been times when you have felt that your transplant affects your life in a less positive way?

(Prompt) Has there been any effect on your social activity?

(Prompt) Has the transplant prevented you from doing things that you used to do?

How aware are you of the kidney on a daily basis?

(Prompt) How often do you think about the kidney?

(Prompt) Do you consider that the amount of thought you give to the kidney has changed over time?

Can you describe what it felt like soon after transplant to have the kidney inside you?

(Prompt) Did it feel like it belonged, or did it feel out of place?

Currently, who do you feel the kidney belongs to?

Have there been any times when you may have felt responsible for the kidney?

(Prompt) Have you ever felt the need to protect it?

Have your thoughts towards the kidney changed over time?

Identity

How would you describe yourself as a person?

(Prompt) What sort of person are you? Happy, anxious, easy going etc.

Has having a transplant made a difference to how you see or feel about yourself?

(Prompt) If so, how do you see yourself now as different to before you had the transplant?

(Prompt) How would you say you have changed?

Do you think that the transplant has changed the way in which others, not your donor, see you?

(Prompt) Members of your family, friends, colleagues?

Do you think that these people treat you differently following your transplant?

(Prompt) In what way?

(Prompt) Could you give me an example?

Relationship with living-related donor

I understand that you received a kidney from your X (Mother / Father / Sister / Brother / Child / Aunt / Uncle / Grandfather / Grandmother). I am interested in your relationship with X, and any possible changes in your relationship.

What was your relationship with X like before you had the transplant?

(Prompt) How close did you feel to X?

(Prompt) How do you consider you got on with X?

Could you describe your feelings towards X now that you've had the transplant?

Do you feel that your relationship with X has changed since the transplant?

(Prompt) In what way has your relationship changed?

Have there been any issues in your relationship which you feel may be due to the procedure?

(Prompt) Could you give me an example?

Has the way in which you've dealt with any issues with X changed since the transplant?

(Prompt) In what way?

(Prompt) Could you give me an example?

Do you consider that X's feelings or behaviour towards you have changed since the transplant?

(Prompt) In what ways?

How have you felt regarding X's health since the transplant?

(Prompt) Have they experienced any problems with their health due to the transplant?

Psychological Processes

Have there been any times since you've had the transplant that have been emotionally challenging for you? I wonder if you could give me an example?

(Prompt) Do you have any other examples?

How have you coped or dealt with any emotional difficulties?

(Prompt) Did you share your difficulties with anyone?

(Prompt) Did you/do you have any particular coping strategies for coping with the transplant?

Could you describe your mood since the transplant?

Has your mood in general changed since the transplant?

(Prompt) Have you felt more or less anxious regarding your health since the transplant?

Do you have any thoughts regarding your future health and the kidney?

Can you identify any positive aspects of having a transplant from a living related donor?

(Prompt) Has the transplant resulted in improved health?

Do you feel the transplant has changed your outlook on life in any way?

Ending

Is there anything else that you would like to add?

Feedback and wind down on the experience of being interviewed.

Review consent and ask about inclusion of any information that is considered too sensitive to include.

Provide debriefing – thanks, any questions, how to contact me, what happens next, dissemination of results.

General Probes

Can you say a bit more about those feelings you have had?

Could you say a bit more about that?

Is there anything else you want to say about that?

Do you have any other examples of when that has happened?

Do you have ideas about...?

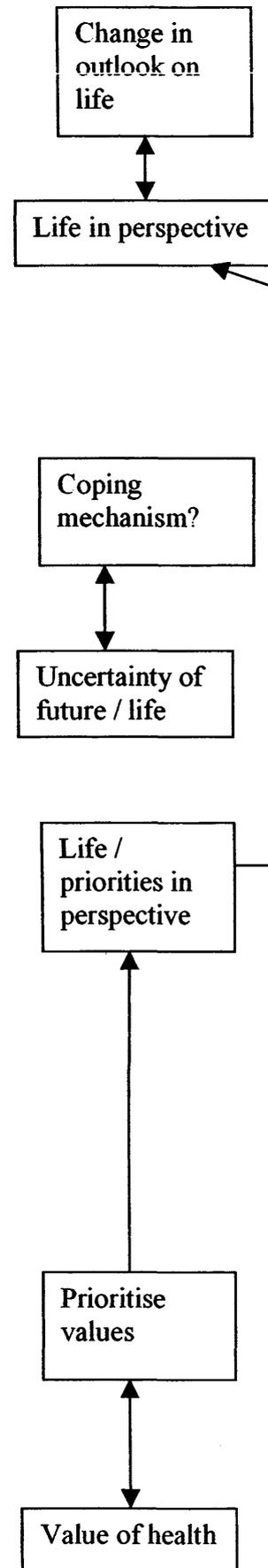
What did you think about that?

What does that mean for you?

How did you make sense of that?

Appendix I. Example of micro-level analysis

Change in outlook	363	J	I think it just cha, it changes your outlook on life because
Big thing to go through	364		obviously y'know, when you've gone through something
Realisation/change	365		like that, you realise that there are things that are perhaps
Makes you prioritise	366		more pressure, more, of, of, of er more value than what's
Life in perspective	367		happening at work or what's happening y'know in the
Acceptance	368		world elsewhere, if, y'know, this is us, and this is our life
Living in the present/ Avoiding thoughts? Coping	369		sort of thing, and I think that's a, y'know, I, I, I've not
Belief reinforced	370		I've never been one of those thinking too much of the
Unpredictability / unexpected	371		future, erm, but I think that, that made it even more
Shock? Unexpected for him and wife/family 'we'	372		certain that, y'know, live for today, y'know, you don't
Ownership. responsibility for life	373		know what's gonna happen, cos you don't in life, and I
Worry = pointless Live for moment	374		think, y'know, we went through that as well and, er that
Life in perspective	375		you realise that you this, this is us, this is our life and
	376		certain things that you worried about previously well
	377		why were you worrying about it?
	378	A	Right. So it put things in perspective?
	379	J	Yeah, well absolutely, yeah.
	380	A	really, right, and is that your outlook still, sort of three
	381		years after the transplant?
Prioritising of values	382	J	Oh yes, very much so, very much so. Y'know, what ever
Transplant = marker of coping/stress? Events compared with transplant – affects their interpretation	383		happens in, in work and other life you think, well, no,
	384		y'know, let's get things in perspective, I've been through
	385		a lot really, erm, and what would be in other things will
	386		be, y'know, I've still got my health still and that's the
Health no. 1 priority / gratitude?	387		most important thing.



Appendix J. Progression of master theme lists

The following tables illustrate the themes identified throughout the analytic process. Themes are renamed and moved throughout the process. Some were made extinct as analysis progressed, as they were not present within subsequent transcripts.

Master theme list following interview 1

Super-ordinate themes	Sub-ordinate themes
Transplant as a defining characteristic of self	Effects on identity Change of role Transplant as a secret
Representation of kidney	Ownership of kidney Offer of a kidney Kidney is a gift Gratitude Looking after kidney Relationship with donor
Process of moving on	Awareness of kidney Recovery New Start

Master theme list following interview 2

Super-ordinate themes	Sub-ordinate themes
Transplant as a defining characteristic of self	Effects on identity Diagnosis Transplant as a secret Dialysis restrictions
Representation of kidney	Ownership of kidney Offer of a kidney Kidney is a gift Gratitude Looking after kidney Relationship with donor
Process of moving on	Awareness of kidney Recovery New Start Longevity of kidney Responsibility to share experiences Appreciation

Master theme list following interview 3

Super-ordinate themes	Sub-ordinate themes
Transplant as a defining characteristic of self	Effects on identity Diagnosis Transplant as a secret How others define you Dialysis restrictions
Representation of kidney	Ownership of kidney Offer of a kidney Kidney is a gift Anticipation
Gratitude	Feeling grateful Desire to repay donor Helplessness at inability to repay donor Looking after kidney
Relationship with donor	Stability of relationship with donor Anxiety regarding donor's health
Process of moving on	Awareness of kidney Recovery New start Freedom Longevity of kidney Responsibility to share experiences Appreciation

Master theme list following interview 4

Super-ordinate themes	Sub-ordinate themes
Story of illness	Effects on identity Diagnosis Offer of a kidney How others define you Anticipation Transplant as a secret
Gratitude	Feeling grateful Kidney is a gift Desire to repay donor Helplessness at inability to repay donor Looking after kidney Ownership of kidney
Relationship with donor	Stability of relationship with donor Anxiety regarding donor's health
Process of moving on	Recovery New start Freedom Longevity of kidney Responsibility to share experiences Anxiety re future origin of kidney Dialysis restrictions Appreciation

Master theme list following interview 5

Super-ordinate themes	Sub-ordinate themes
Story of illness	Diagnosis Offer of a kidney Anticipation
Kidney is a gift	Feeling grateful Ownership of kidney Desire to repay donor Helplessness at inability to repay donor Looking after kidney
Coping mechanisms	Resuming life Transplant as a secret
Uncertainty of future	Longevity of kidney Anxiety re future origin of kidney Worries of donor's health
Process of moving on	Recovery Relationship with donor New start Freedom Dialysis restrictions Appreciation

Master theme list following interview 6

Super-ordinate themes	Sub-ordinate themes
Story of illness	Diagnosis Being offered a kidney Anticipation
Kidney is a gift	Feeling grateful Ownership of kidney Desire to repay donor Helplessness at inability to repay donor Taking care of kidney
Uncertainty of future	Longevity of kidney Future origin of kidney / availability Worries of donor's future health Dialysis restrictions
Coping mechanisms	Resuming life Transplant as a secret = minimising difference Relationship with donor = stability
Liberty	New life Freedom Appreciation

The master theme listed developed following interview 6, remained unchanged following interviews 7 and 8, reinforcing its accuracy.