Illuminating donor and recipient experiences in live kidney transplantation

A Thesis submitted for the degree of Doctor of Philosophy

By

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DECLARATION

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

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Abstract
Live kidney transplants are a successful and efficient means of treating those with chronic renal failure. However, the procedure is associated with potential physical and psychosocial risks, such as operative complications and pressure to donate and receive. Recipients also often feel grateful, even 'indebted', to the donors and, consequently, this can affect their relationship with each other.

Despite these issues, few studies have focused on the experiences of those involved in live transplantation. This study was, therefore, undertaken to provide an in-depth insight into this process from the participants’ perspectives. Therefore, the aims of this qualitative, longitudinal study were to explore:

➢ The experiences of donors and recipients throughout the live transplantation process
➢ The relevance of the anthropological theory of 'gift exchange' as a framework for exploring and understanding the live kidney transplantation process
➢ How a theoretically informed insight into these experiences may be used to inform and develop future research and clinical practice

A qualitative, phenomenological approach was used to explore the experiences of 11 live kidney donors and their recipients in South-West England. Data were collected through a series of three semi-structured interviews, conducted pre-transplant and at three and ten months post-transplant. Interviews were transcribed verbatim and data coded into categories arising from participants’ accounts. These findings were also considered within a theoretical framework of gift exchange.

Live transplantation was the treatment of choice for all participants, especially recipients. All donors initially made an instantaneous, voluntary decision to donate and found the decision relatively easy to make. In contrast, recipients found accepting the donors’ offer emotionally burdensome because of concern for their wellbeing. They were only really able to accept the transplant after discussing the matter with their donor and establishing that it was something that they really wanted to do.
Recipients' lives were transformed by a successful transplant and they were subsequently very grateful to the donors for donating. Donors derived immense personal satisfaction from this outcome and it helped to confirm to them that what they had done had been worthwhile. However, the transplant rejected in one recipient and the effects of this failure were devastating. The provision of transplant services throughout this process were generally positively evaluated by participants, although several recommendations were suggested.

Data from this study show that the experiences of participants interviewed, closely resembled the fundamental dynamics of the gift exchange process, thus supporting the hypothesis that this theory provides an appropriate framework for understanding the live transplantation process in these participants.

The findings from this study have implications for clinical practice and future research in this area.
**Glossary/Definitions**

**Continuous Ambulatory Peritoneal Dialysis (CAPD)** – a method of dialysis in which a special solution is run through a tube in the peritoneum (a thin tissue that lines the cavity of the abdomen and acts as a semi-permeable membrane). The body’s waste products are removed through this tube. This form of dialysis is often performed at home.

**Chronic Renal Failure (CRF)** – inability of the kidneys to function properly, due to progressive, irreversible failure.

**End-stage renal disease (ESRD)** – chronic renal failure that leads to severe illness and requires some form of renal replacement therapy (e.g., dialysis).

**Erythropoietin** – a hormone formed in the kidneys from a plasma protein that stimulates erythrocyte (red blood cell) formation.

**Dialysis** – The generic process of separating small molecules (e.g., urea) from large (e.g., plasma proteins) by the difference in their rate of diffusion through a selectively permeable membrane.

**Haemodialysis (HD)** – filtering of the blood by means of an artificial device (dialysis machine) so that certain substances (e.g., water, urea and creatinine) are removed from the blood as a result of the difference in rates of diffusion through a selectively permeable membrane, while the blood is being circulated outside the body.

**Haemoglobin (Hb)** – a substance in erythrocytes (red blood cells) involved in the transportation of oxygen and carbon dioxide.

**Unrelated Live Transplant Regulatory Authority (ULTRA)** – A committee established in the UK in 1990 to consider applications made by registered medical practitioners seeking approval to transplant an organ between two living unrelated (genetically unrelated) people.
The researcher’s perspective

Koch (1996) argues that researchers should closely examine the reasons for selecting a particular phenomenon for study and take every possible opportunity in the study to explain the choice because, it is argued, these choices stem from the researcher’s own predispositions and values. This seems particularly relevant to research such as this study that are guided by Heideggerian hermeneutics, since interviewers subscribing to this philosophical approach presuppose that they bring their preconceptions to the research study (unlike Husserlian transcendental phenomenology, which presumes that interviewers can lay aside their preconceptions) and they should, therefore, acknowledge themselves as part of the research process (Koch 1995, Walters 1995, Paley 1997, Lowes and Prowse 2001). Phenomenology, as a philosophy and a research approach, are critically discussed in the methods chapter of this thesis (p88 -).

Consequently, a defining quality indicator in Heideggerian research is a detailed explication of the researcher’s preconceptions and reference to these throughout the research process (Lowes and Prowse 2001). Therefore, it is, perhaps, wise for me, at this stage, to clarify my beliefs and position about the study phenomenon as the decision to perform this study is surely based on these fundamental issues. I feel that a personal autobiographical exposition is therefore required as it does form part of the ‘audit or decision trail’. That is, such an approach provides readers with an insight into one’s thinking process and allows researchers to properly address questions that are crucial to the research process such as explaining theoretical assumptions and identifying factors that made researching
the subject area desirable. By doing this, readers are in a far better position to assess the degree to which researchers have been self critical (Silverman 2000).

I qualified as a registered general nurse in January 1992 and initially worked on a general medical unit for several months before taking up the position of staff nurse in the intensive therapy unit (ITU) at the hospital where I trained. Since then, I have spent most of my clinical nursing career working in various ITUs across South Wales. Whilst working in ITU, I became intensely interested in organ donation, though initially just from an ITU perspective, which generally involves working with and caring for brain-stem dead patients and their families. As such patients are the major source of transplantable organs in the UK, virtually all families of brain-stem dead patients, who are potential multi-organ donors, are approached by ITU staff and, through a structured, sensitive, multi-disciplinary approach, are respectfully asked about the option of organ donation.

Although this aspect of intensive care nursing is personally and emotionally demanding, it is also a particularly rewarding facet of the job. Primarily because this particular role involves building up a rapport with the family and friends of the patient, providing them with structured, understandable information, answering their questions and concerns, supporting them throughout such a difficult period and working closely with other members of the ITU and transplant multi-disciplinary team (most notably the transplant co-ordinator).

I soon became so interested in the field of organ donation that I began to read, write, publish and lecture on the subject. I also spent some of my own time with the local transplant co-coordinator, following up families of multi-organ donors
who I had cared for in ITU. The primary reasons for these visits were to see how the families were coping and what they now thought of their decision to agree to organ donation.

All of the families that I visited with the co-ordinator were probably coping as well as most families who have recently experienced a bereavement. However, all families were very positive about their decisions to proceed with donation and all were heartened on hearing who, generically speaking, the organs had gone to and how well the transplant recipients were now doing. In the several families that I visited, this information appeared to confirm to them that they had done the right thing and many confessed that this was now a source of comfort to them.

This interest in multi-organ donation has since spread to all aspects of organ donation, particularly live kidney transplantation. However, my actual clinical nursing experience in this area is relatively limited, as it generally remains confined to caring for prospective cadaver donors and their families in the ITU environment. I soon began to read extensively about live kidney transplantation and quickly realised that it was a rapidly growing phenomenon, primarily because of the benefits (improved graft survival rates), the relatively low associated physical risks for both donor and recipient and because of the increasing shortage of human cadaver kidneys (BTS/RA 2000, Calder and Chang 2004, Wafa et al 2004).

However, I also established that the personal dimensions of live kidney transplantation, such as the individual experiences of donors and recipients
throughout the transplant process and their perspectives of service provision, were relatively poorly explored, particularly in comparison to the physical dimensions of transplantation, such as graft survival rates. I felt that this lack of insight and understanding of the transplantation process meant that it was unclear how such families coped throughout this process or whether the health care service provided to them adequately met their needs.

During 1998-1999, I took a career break and studied full time for a Masters degree in social anthropology at the University of Oxford. It was during this time that I first learnt about the concept of the ‘Gift Theory’, which I found compelling. As discussed in literature review, the concept of gifting was first discussed by anthropologists in the early 20th century and represents a way of exchanging goods, in the absence of money, and of developing social relationships with others.

Whilst writing on the topic for a supervisory tutorial, I realised that the gift theory did, potentially, have considerable relevance to organ donation in general and live kidney transplantation in particular, because of the reasons discussed in the literature review. I then undertook further reading on this subject and discovered that the theoretical association between gifting and organ donation (though mainly from a cadaveric perspective) had already been made by many healthcare academics, charities and procurement agencies. However, despite the potential theoretical benefits that the gift theory could offer patients, families and health professionals directly involved in live transplantation (as discussed in the
literature review), there is virtually no direct empirical evidence that supports, or refutes, the relevance of gifting to live kidney transplantation.

I therefore wanted to explore the experiences of live donors, recipients and their significant others (e.g., spouses not undergoing transplantation, as the process often also has a profound impact on them) throughout the live transplantation process and to explore the potential relevance, or not, and benefits of the gift theory to this process and to families living through the experience. I believed that to provide better standards of care and support to patients and their families involved in live kidney transplants, there was a need to develop a greater understanding of these families’ experiences of the process and existing provisions of care. This was, therefore, my primary reason for undertaking this study.
Introduction

This introductory chapter, and subsequent review of literature, will use a variety of appropriate national and international literature and research in order to provide a critical insight into the nature and extent of the research problem and the need, and justification, for further empirical research.

End-stage renal disease (ESRD) is a condition whereby renal tissue is irreversibly destroyed (Killingworth 1993). Although there are a number of contributory factors, the condition is most commonly caused by hypertension and diabetes (Coombs et al 1993, Murray and Conrad 1999). ESRD is a chronic, debilitating illness that affects many aspects of the sufferer’s and their family’s life. Common problems include lethargy, declining health, lifestyle changes, altered social roles, demanding treatment regimes, changes in body image, reduced sexual activity, unemployment, financial hardship, fear, anxiety and depression (Brunier and McKeever 1993, Cook 1995, Christensen and Ehlers 2002).

However, although the condition is chronic, there are a variety of treatment options available, including haemodialysis (HD), continuous ambulatory peritoneal dialysis (CAPD) and transplantation. Unfortunately, dialysis often has to be performed several times each week, either in hospital or at home, with each session lasting up to several hours. Consequently, as many patients must undergo this rigorous regime for several years, dialysis is physically and emotionally demanding for the patient and their family and is financially expensive to the National Health Service (NHS).
Kidney transplants are therefore generally recognised as the best treatment option for most patients (British Transplant Society/Renal Association - BTS/RA 2000, Hariharen et al 2000). A successful transplant can offer almost complete physical recovery from ESRD, thus greatly improving quality of life. It may also actually increase long-term survival and, compared with a prolonged period of dialysis, is the most cost effective form of treatment (Murray and Conrad 1999, BTS/RA 2000, Trevitt et al 2001).

Unfortunately, the United Kingdom, like most countries, has a long and ever increasing waiting list for transplantable organs. At the end of 2005, a total of 8111 people were awaiting organ transplants in the UK, with most (7256, 89%) awaiting kidney transplants (UK Transplant 2006a). Consequently, many patients often have to wait several years for a suitable organ to become available and some, unfortunately, die before an organ is found.

This, coupled with an ever-increasing transplant waiting list, means that live related transplants not only represent an effective intervention for patients with ESRD, but for many patients, it also means less time on the transplant waiting list and/or dialysis, with some pre-emptive transplant recipients avoiding the need for dialysis altogether.

There are also certain reported benefits for the live donor. For example, the intensive medical investigations that the potential donor must routinely undergo means that, occasionally, undiagnosed medical problems are identified and can be treated. Also, because the recipient’s life is often transformed, or even saved, there is often an associated psychological benefit, with many live donors experiencing a boost in self-esteem following transplantation (Simmons et al 1987, Lumsdaine et al 1999, Cabrer et al 2003, Stothers et al 2005).
However, despite such reported benefits, live transplants are not without physical and psychosocial risks (explored further, page 66-). For example, both donor and recipient are at risk of operative complications associated with a general anaesthetic and a major surgical procedure, such as a pulmonary embolism, infection, graft rejection and, in rare cases, even death (BTS/RA 2000). There is also a very real possibility that some live donors may feel emotionally compelled or pressured into donating an organ to a family member simply because they are related (Tabok 1994, Fox and Swazey 2002).

The whole transplant process is, potentially, very emotive and consequently may also have a significant impact on the lives of other close family members. For example, spouses of potential donors may be very concerned about their partner’s health before, during and after the act of transplantation (Hilton and Starzomski 1994). Live transplants can also have financial implications for the donor and their immediate family because, at present, some donors are often unable to claim full sickness benefits post-operatively because they have voluntarily entered into a major surgical procedure that is not for their own personal benefit. Therefore, given such issues, it is also important to extend care and support to the families involved throughout the transplant process whenever and wherever possible (Morris et al 1987).

However, although a number of serious decisions confront the patient and family considering a live kidney transplant, no clear guidelines are available to help them through the experience (Hilton and Starzomski 1994). Unfortunately, despite the excellent results of live transplants, an extensive search of the
literature reveals that few studies have actually paid any attention to either the live transplantation process or the experiences and perspectives of the families involved. This lack of empirical evidence means that it is unclear whether the standard holistic care currently provided to those involved in live transplants adequately meets their needs. Therefore, a greater empirical and theoretical insight into the decision making process and the experiences of those involved could be used by health professionals to guide and inform the provision of appropriate person-centred care and support for such patients and their families.

It is possible that the anthropological theory of 'gift exchange' could be used to improve the theoretical understanding of the live transplantation process. For example, it has been frequently postulated that the gift exchange theory could be effectively used by health professionals to better comprehend important issues such as the decision making process and the pressures and motivations involved in the potential obligations to give, receive and reciprocate in live transplantation (Conrad and Murray 1999, Fox and Swazey 2002). However, despite the considerable publications on the theme of gifting in healthcare, particularly in the field of organ donation, the potential relevance of this framework has never been empirically tested, with many writers merely referring to the theory somewhat naively, often with little or no critical thought as to whether the framework is actually useful or even applicable in the context of healthcare.

The opening chapters of this thesis will, therefore, critically explore the anthropological theory of gift exchange and the potential relevance this framework has to the field of healthcare, focusing on blood, ova, bone marrow
and organ donation, particularly live kidney transplantation. The subsequent chapter will explore the perspectives and experiences of families involved in the live transplantation process.

Chapter four will identify the research questions and discuss the research process used to conduct the study. Chapters five, six and seven will respectively present data from interviews conducted pre-transplant and at 3 and 10 months post transplant. The subsequent three chapters will critically explore the interpretation of the data, respectively focusing on transplant service issues, analysis of key findings and a consideration of the theory of gift exchange as a framework for understanding the live transplantation process. The final chapter in the main body of the thesis will draw together the key study findings and discussions into a coherent conclusion and will make appropriate recommendations for future research and clinical practice.
CHAPTER ONE: The theory of gift exchange

1.1 Introduction

This opening chapter will critically explore the anthropological theory of gift exchange, and its associated range of implications, focusing on how and when the theory of gift exchange was originally developed and how, through a series of examples, the gift exchange system operates. The review will also discuss how gifting operates in contemporary society and will provide a critical analysis of Mauss's work.

1.2 The gift

The theory of 'gift exchange' was developed by the French social scientist Marcel Mauss (1990). Mauss came from a family of distinguished social scientists, which included Emile Durkheim (his uncle) and Robert Hertz (his cousin). Mauss, however, never actually undertook any anthropological fieldwork throughout his entire academic career. He therefore developed the theory of gift exchange from the fieldwork of other anthropologists, particularly Malinowski.

Mauss (1990) originally published his now famous book 'The Gift', which explores the form and reasons for gift exchange in non-industrialised (referred to as 'primitive') societies, in French in 1925. However, at that time, the book made little international impact, probably, in part, because it was published in French. The book finally received international acclaim following its translation into English in the early 1950s.
The system of gifts-through-exchange described by Mauss (1990) is now widely regarded as the first, or most primitive form of economy known to man (Douglas 1990). An economic system that differs quite radically from the modern economies that now exist in most societies across the world, particularly in the Western hemisphere. Modern economies are primarily based on 'market' or 'commodity' principles, whereby goods, such as food and clothes, are bought and sold using cash or the equivalent (for example, credit cards). However, in the early 1900's, Mauss (1990) discovered that some small, non-industrialised societies found along the North-West coast of America, the Pacific islands of Polynesia and Melanesia and some Australian Aborigine tribes lacked properly developed market-based economies. This was probably partly due to the fact that, at that time, proper money with which to trade, was either absent or severely insufficient. Therefore, the primary system of exchange and contract in these societies, although not totally devoid of market principles, largely took place in the form of gifts or presents (Levi-Strauss 1967, Douglas 1990, Mauss 1990).

Mauss (1990) surmised that, despite the façade that gifts are voluntary, they are, in fact, obligatory. Mauss (1990, p. 49) states:

'Gift exchange is, essentially, a form of contract governed by three major concepts; the obligation to give, the obligation to receive and the obligation to repay (reciprocate)' (see Figure 2).

Giving is seen to create a sense of 'indebtedness' in the receiver. The person who receives the gift is, therefore, obliged to reciprocate, occasionally with interest, the present that has been received. Failure to do so will result in the receiver being considered ungrateful and even inferior (Mauss 1990).
Figure 2. The gift exchange framework

Adapted from Sque and Payne (1994).
Besides providing a basic form of economy, in the absence of money, Mauss (1990) discovered that gift exchange also permeates much of the economic, tribal and moral life of the people in the societies explored. Mauss (1990) wanted to show that exchange in these ‘primitive societies’ consists not so much in economic transaction but in reciprocal gifts that have important functions in these societies (Levi-Strauss 1969). This primitive form of exchange is not merely, nor essentially, of an economic nature but what he refers to as ‘a social phenomenon’ - that is, an event that has significance that is social, economic, sentimental and moral (Levi-Strauss 1969).

1.3 Types of exchange

In The Gift, Mauss (1990) differentiates between two different kinds of gift exchange. For example, the people of the Trobriand Island of Melanesia, distinguish between *gimwali* – the straightforward economic exchange of useful goods – and *kula* – a ceremonial exchange of gifts (Malinowski 1922). For the Trobrianders, there were occasions for trade (*gimwali*) and occasions for gift (*kula*), though both are the means for circulating goods among groups (Murray 1987).

Among some Native American Tribes found along the Northwest coast of Alaska and Canada, there also exists a similar type of ceremonial gift exchange. However, this ceremony is referred to as *potlatch*, a Nootka Indian word for gift (Levi-Strauss 1969).
Unlike the normal exchange of goods for trade purposes, which takes place on a regular basis, the ceremonial exchange of goods, in both kula and potlatch, generally only takes place on certain important occasions, such as births, weddings and deaths (Levi-Strauss 1969, Mauss 1990). The actual gifts exchanged on such occasions vary but often include objects such as bracelets, jewellery, clothes, weapons and food (Levi-Strauss 1969). The ceremonies of kula and potlatch also differ from the normal system of gift exchange for trade purposes in that both are systems of ‘competitive gift exchange’.

In the kula ceremony, a person initiates a cycle of exchange by giving a gift (for example, a bracelet; mwali) to another person with whom he wants to exchange. This is referred to as the opening gift (voga) (Malinowski 1922). The person receiving the gift is then indebted to the giver and is, therefore, irrevocably committed to the exchange cycle. The recipient is under social and moral pressure to ‘balance out’ the exchange by returning the giver something of equal worth (Sque and Payne 1994). This is referred to as the clinching gift (yotile) (Malinowski 1922). It is obligatory, expected and must be comparable to the first gift or ‘revenge’, usually in the form of public humiliation or loss of status, may be taken (Mauss 1990).

The aim of the exchange is to display generosity, freedom, autonomy and even greatness and yet, overall, it is mechanisms of obligation that are called into play (Mauss 1990). Furthermore, the exchange of gifts does not stop after this first exchange. Once entered into the initial exchange, both partners are committed
into a perpetual chain of obligatory gifts and counter-gifts. To pull out means to lose face, rank or respect in society (Mauss 1990).

In the system of *potlatch*, tribal chiefs are obliged to initiate exchange cycles with their people by offering gifts such as food and jewellery. However, in these societies, the obligation to accept is equally compulsory. To refuse a gift, or to refuse to attend a *potlatch*, is to show that one is afraid of having to reciprocate (Mauss 1990). As in *kula*, once a person has received a gift they are 'indebted' to the chief, or to another person with whom they are exchanging, and must, therefore, reciprocate the gift. However, as *potlatch* is also a system of competitive exchange, the gift must be reciprocated with interest of around 30-100% per annum (Mauss 1990).

The formal or legal rules that govern these exchanges are unclear, probably for two distinct reasons. Firstly, Mauss (1990) had to rely on the field-notes of other anthropologists. Consequently, besides being second-hand, some of his data were limited, which, in this instance, severely affected his ability to probe participants further. It would appear, though, that the other reason for the ambiguity is due to the fact that it is gifts, and not contracts, that are being exchanged. As Murray (1987) points out, gifts, by and large, carry no formal legal obligation whatsoever. However, because of this, the obverse is also true; that is, anything not explicitly required 'in the contract' is permitted (Murray 1987). Both Murray (1987) and Mauss (1990) maintain that it is probably because of this tacit phenomenon that gifts often entangle people in significant, yet vague, moral obligations.
1.4 The energy of the system

The question that arises when exploring the concept of gifting, particularly of a competitive nature (*kula* and *potlatch*), and one which Mauss (1990) himself asks, is exactly what energy drives the entire cycle of exchange? What compels people to give, receive and reciprocate in such a rigid fashion? In the system of gift exchange that Mauss (1990) describes, giving, receiving and reciprocating are not just morally desirable but obligatory. But is obligation, alone, motivation enough to drive the entire process? The answer is, most probably, no. Even in a society where gift exchange is the cultural norm, mere obligations are not the only reason for people actively participating in gift exchange.

The gift exchange theory is, in fact, largely driven by a variety of factors, such as duty, obligation, honour, respect and, particularly, self-interest. As Strathern (1992) maintains, when people give gifts they often do so, perhaps unknowingly, from their own vantage point. For example, it would appear that the main reason for participating in a system of gift exchange, particularly of a competitive nature, is to improve one's social standing in society, to obtain more power and respect, or to establish some kind of desirable clan link between partners (Mauss 1990). The greater the things exchanged, the more power and respect a person can obtain. It is not, after all, states Levi-Strauss (1969), the mere possession of wealth that gives prestige in the societies that Mauss (1990) describes but rather its distribution.

For example, in the *potlatch* ceremony, the tribal chief is obliged to give gifts to his people to maintain his rank, authority, respect and his family’s position in
that society (Mauss 1990). However, the remainder of the population give, not to maintain their status within society, but to improve it. The more or the greater the gifts a person has to give, the more likely they are to enter into a competitive exchange cycle with a richer, more powerful person. The person initiating the exchange, therefore, hopes to surpass his rival in generosity, to crush him, if possible, of future obligations, which it is hoped he cannot meet (Levi-Strauss 1969). If and when this occurs, the person initiating the exchange will then take from his more powerful partner his title, rank, authority, respect and prestige, thus ‘promoting’ himself and his family.

Failure to give can result in humiliation, loss of prestige and loss of rank in the society (Mauss 1990). However, receiving also carries comparable obligations. Mauss (1990) states:

‘The obligation to accept is no less constraining. One has no right to refuse a gift, or to refuse to attend potlatch. To act in this way is to show that one is afraid of having to reciprocate, to fear being flattened (losing one’s name) until one has reciprocated. To refuse is to admit defeat in advance’ (p. 52).

Ultimately, giving, receiving and reciprocating is a matter of honour. Respect, power and status must always be maintained, even if it means bankruptcy.

There are, though, some other equally important reasons that drive the system of gift exchange in these non-industrialised societies. For example, a common belief in the societies described by Mauss (1990) is that failure to give, receive or reciprocate could lead to some sort of punishment from the ‘spirits or ancestors’ (Douglas 1990). This fear of unspecified ancestral punishment also helps to enforce reciprocation and hence the cycle of exchange is perpetuated.
1.5 The ethos of the gift

Gift exchange has two very important functions. Firstly, it is a simple, efficient way of exchanging essential goods, such as food and clothes, in the absence of money. However, secondly, and perhaps more importantly, it is a very effective way of establishing and, thereafter, sustaining mutually desirable relationships with others.

Gift exchange can lead to the formation of important alliances between individuals, families, tribes and societies. As Levi-Strauss (1969) points out, the purpose of normal reciprocal gift exchange in these societies is primarily a moral one, since nobody really gains anything from an economic viewpoint but, instead, the trade generally produces a friendly feeling between the people concerned. Malinowski (1922) observed that the relations formed through gift exchange are among the most powerful that bind social groups together.

The formation of friendly relationships in small, non-industrialised societies are essential for they offer, amongst other things, increased collaboration, reduced hostilities, safety and intertribal marriage benefits. It is because of this phenomenon that the theory of the gift is recognised as a theory of human solidarity (Douglas 1990):

'If friends make gifts, gifts make friends'
(Sahlins 1972, p.186).

As Douglas (1990) adds, a gift that does nothing to enhance solidarity is a contradiction.
1.6 The market versus the gift

There are several fundamental differences in economies based on gift exchange and those based on market principles. Parry and Bloch (1991) argue, quite reasonably, that western economic systems, governed by monetary exchange, have helped to dissolve the bonds between persons based on kinship and other obligations, as money allows possession ‘at a distance’. For example, whilst customer relations may very well be important to most large companies, it is generally profit and not the formation of close personal relationships that is of primary importance. Also, for the consumer, it is generally the product that the company offers, (though price and quality issues are also imperative) and not the relationship that is important. Consumers can also select where to shop and who to buy from. They do not necessarily need, or have, to know from whom they are purchasing and, consequently, the ‘market’, particularly when compared to the ‘gift’, is recognised as being impersonal.

Gifting, however, is, by its very nature, a highly personalised form of transaction where the actual exchange of goods is often secondary in importance to the relationship itself (Murray 1987, Strathern 1992). If a gift is given spontaneously, it is usually because there is a pre-existing close personal, perhaps even intimate, relationship between the giver and the recipient (Gerrand 1994) and it is here that gift exchange differs quite radically from ‘the market’.

Because gift giving is a personal transaction, the gift itself is also likely to be personally significant to both the giver and the receiver (Gerrand 1994). As Strathern (1992) maintains, gifts are never free standing, they have value because
they are attached to one social source (giver) in being destined for another (receiver) and therefore carry identity. For instance, an individual can usually associate a particular, significant gift that they have received (for example, a piece of jewellery) with the person who originally gave it to them. It is because of this that gifts are said to carry with them something of the giver. Mauss (1990) refers to this phenomenon as ‘the spirit of the gift’. The gift always carries with it a ‘spirit’ or ‘soul’, an element of the person who gave it; hence it follows that to make a gift of something to someone is to make a present of some part of oneself (Mauss 1990). Through ‘the spirit of the gift’, the giver has a hold over the beneficiary and this also reinforces the cycle of exchange (Sque and Payne 1994).

1.7 Gifting in present day society

Whilst The Gift (Mauss 1990) is by no means flawless, the book is now widely regarded as a classic in modern social anthropology (Levi-Strauss 1967, Douglas 1990, Godbout and Caille 2000). Mauss (1990) was unique in being the first anthropologist who managed to effectively encapsulate society, economy, kinship and religion in one single book. Before this work, most anthropologists had tended to treat such features as totally separate entities (Douglas 1990).

However, the other reason that The Gift (Mauss 1990) is still held in high esteem is because of its enduring features. That is, despite being 75 years old, the logic of the gift is not only relevant to ‘archaic societies’ but, though occasionally in more subtle ways, also to modern societies (Godbout and Caille 2000).
Although most gift economies have now been replaced by exchange for profit, gift exchange continues to pervade much of contemporary life, though often in a less rigid fashion than in The Gift (Mauss 1990). This is particularly apparent on birthdays, at Christmas and can also be seen through invitations and volunteer work. However, most non-anthropologists probably find the concept of gifting, as described by Mauss (1990), somewhat confusing, largely because it belongs to a time and/or place that few can appreciate or properly understand. The easiest way, therefore, to expand on Mauss’s work is to explore the relevance of gifting in modern day society, in situations that are easier to relate to.

Whilst there are many useful examples of gifting in contemporary society, Levi-Strauss (1969) uses an effective analogy of wine sharing amongst two strangers in a restaurant in France to demonstrate the intricacies of an exchange system. The story follows that two complete strangers are sat alone at different tables in a bistro. One stranger offers the other, with no pressure to do so, some of his wine. The other person accepts the wine graciously. However, when both glasses are empty, the recipient then offers the initial giver some of his wine. From an economic viewpoint, no one gains or loses, but there is more to the exchange than the things exchanged (Levi-Strauss 1969). It is the basic assertion of good grace and does away with mutual uncertainty – wine offered calls for wine returned. Thereafter, relations can only be cordial (reciprocation) or hostile (non-reciprocation). However, the person who initiates the process is at greater social ease for taking the initiative, and this, theoretically, puts him in an advantageous position (Levi-Strauss 1969). That is, the creditor/debtor relationship to which Mauss (1990) refers. Levi-Strauss (1969, p. 60) adds:
We are faced with a ‘social phenomenon’, on a microscopic scale it is true, the implications of which are social, psychological and economic.

Through this analogy, Levi-Strauss demonstrates how, in theory, the gift exchange system operates and how it can help create relationships, however transient they may be.

The wine sharing analogy is quite easy to relate to, probably because most people have, at some point, either been involved in sharing drinks with others or buying rounds of drinks with friends. The interesting thing, though, about buying a round of drinks is that by the end of the round everyone has paid, in principle, for what they have consumed, because there are usually as many rounds as people present (Godbout and Caille 2000). However, the relationship established, or maintained, is, arguably, more important that what occasioned it (Godbout and Caille 2000). The other principles of the exchange, as with Levi-Strauss’s (1969) analogy, is that once entered into the round of drinks, a person is committed, though not irrevocably of course. However, to pull out or to refuse to buy a round of drinks in return, having already consumed the drinks bought, would be discourteous and probably disapproved of by the others. So, again, even though a drink may be bought with no reciprocal intention, the receiver often feels compelled to repay and, consequently, the exchange usually continues until everyone has bought their round. The round can then continue or end there with ‘no debt incurred’.

The most common example of contemporary gifting, however, is the annual exchange of gifts at Christmas in most Western societies. Nourished by the myth
of the greatest gift possible (a God born to give His life for humanity), the festive season is that period of the year during which the world of the gift, usually lodged in the cracks of modern society, takes centre stage (Godbout and Caille 2000). Levi-Strauss (1969) maintains that the ritual exchange of Christmas presents, practised by millions the world over, with a sort of sacred ardour, is nothing but a gigantic potlatch, at the end of which, many family budgets are faced with a lasting disequilibrium.

The distinctive thing, though, with Christmas presents is that they are all usually gift-wrapped. This helps to express the personal, intimate bond between the giver, the gift and the recipient (Levi-Strauss 1969). The wrapping also hides what is in circulation, thus demonstrating that what counts is not the hidden gift but, instead, the gesture (Godbout and Caille 2000).

As with traditional gift exchange described by Mauss (1990), other similar principles are also in force at Christmas time. For example, when a person receives a Christmas present, particularly if it came from a person who they originally had no intention of buying for, they usually feel compelled, perhaps even obliged, to reciprocate. Failure to exchange Christmas presents would be insulting and rude to the person who gave the present (Murray 1987). Most people would also probably feel uncomfortable if a person had bought them a gift that was clearly of greater value than the one that they had bought for them. Furthermore, as in traditional non-competitive gift exchange, nobody really gains anything from an economic viewpoint at Christmas, but, of course, this is not really the purpose of exchanging Christmas presents. Finally, Levi-Strauss
maintains that Christmas reminds us that, even in our own society, the distribution of wealth is a way to gain prestige. However, here Levi-Strauss's choice of words is, arguably, inappropriate. Admittedly, giving Christmas presents is a way of gaining gratitude and appreciation, but the reality is that, today, probably very few people give gifts at Christmas purely to gain prestige.

A final example of contemporary gifting is that of voluntary work as, for example, found in Alcoholic Anonymous (AA) self help groups. This sector hews to the spirit of the gift insofar as the founding of these associations is a voluntary act, they are self financing, disinterested in profit and provide a valuable service based, largely, on volunteer work with no expectation of reciprocity (Godbout and Caille 2000). Each AA meeting often consists of the group listening to one or more members talking about their alcohol problems. This is referred to as 'sharing'. One of the fundamental principles for self help groups, it would seem, is that helping is therapeutic and, it is hoped that in the act of helping others, a solution to one's own problems may be found; consequently, to give and receive become indistinguishable (Godbout and Caille 2000).

What is quite unique about members of AA is that once they have 'recovered', many go on to become volunteer helpers of the organisation. The rationale behind this, it would seem, is that the individual has received so much help, encouragement and support from the group that they want to 'give something back' to the organisation (Godbout and Caille 2000). Many volunteer workers, and this is probably not exclusive to AA members, maintain that they receive a
great deal of pleasure from what they do and this is one of the prime motivating factors for their actions (Godbout and Caille 2000).

It would appear that for volunteer workers, there is often no material return from their actions of the kind to which Mauss (1990) refers. However, as the above example demonstrates, there often is a return and it is significant.

1.8 Features of the modern gift

In contemporary society, little attention is paid to the principles or intricacies of gifting. Yet the intricacies (obligations) of the gift exchange system persist, perhaps unknowingly or unthinkingly in the modern mind. Perhaps these 'obligations' are not always as powerful as they once were but they are still there, all the same.

When thinking of gifts, a common assumption is that they are not, in fact, obligatory and, therefore, Mauss's (1990) framework is far too rigid for today's society. Most people would probably maintain that it is possible to give a gift to another person with absolutely 'no strings attached'. But is a totally free gift ever really possible? This question has caused considerable debate amongst anthropologists, but most authors writing about the gift maintain that a gift can never really be totally disinterested (free) (Godbout and Caille 2000). It seemed to Mauss (1990), and has seemed to a great many anthropologists since, that a genuinely free gift would play no part in the creation of social relations, for it would create no obligations or connections between persons, and therefore, even
if such a thing existed, it would be of no serious interest to anthropology (Laidlaw 2000).

People often give gifts to their friends, relatives or partners simply because they want to or, for example, because they are unhappy and they hope that a gift may cheer them up. These individuals also probably think that they do not want anything at all in return from the recipient, in which case the gift could be regarded as being free. However, even though most people may not expect a material return from their gift of the kind to which Mauss (1990) refers, the reality is that they often do expect something back. For example, as demonstrated through the earlier example of volunteer work, there are a variety of non-material returns from a gift such as the gratitude and appreciation it inspires, the pleasure of giving and the links it creates, which supplement any circulation of material goods and do not enter into the 'accounting', and these all represent important returns for the giver (Godbout and Caille 2000). Often, if this return is not apparent, then the gift giver is usually left feeling disappointed and perhaps even hurt and dejected. Simply recall an occasion when someone treated with indifference a gift that you had regarded as special and important, in some ways the rejection of the gift was a personal rejection (Murray 1987).

This helps to demonstrate that certain obligations are still expected from recipients of gifts. Anybody who has ever received a gift, however small, is most probably aware of the need to appear grateful to the giver, regardless of whether they really liked the gift or not. To ignore this unspoken rule would most probably be construed as being ungrateful and could, possibly, harm the existing
relationship between giver and receiver (Murray 1987). The surprising thing about this 'grateful conduct' is that both giver and receiver know it exists, though perhaps only subconsciously, and it is only when it does not occur that offence may be taken.

It would be very unlikely for an individual to buy a personal gift, such as a box of chocolates, for a complete stranger and not expect anything at all in return, not even a thank you or the slightest show of appreciation. Such an act, if it was to occur, probably could be regarded as disinterested (free). However, the reality is that most people give gifts for a particular reason. For example, for pleasure, as a matter of conscience, to cheer someone up or simply as a token of friendship or companionship, all of which help to demonstrate that gift giving generally remains a personal act, which, much like the 'primitive gift', helps to sustain mutually desirable relationships. Gifts, states Murray (1987), benefit the other and the self, an interesting yet strange amalgam of altruism and self-interest. However, if we persist in thinking that gifts ought to be free and pure, we will always fail to recognise our own cycles of exchange, which categories get to be included and which to be excluded from our hospitality (Douglas 1990).

The 'spirit of the gift' also persists in the modern gift, though perhaps in a weaker form than in the 'primitive' gift. For example, an engagement ring, although always associated with the occasion, will also always be associated with the giver. Therefore, an engagement ring will, during the course of the relationship at least, always carry with it great sentimental value to both parties, even if its monetary value is small.
According to Mauss (1990), the acts of giving, receiving and reciprocating are obligatory. However, in today’s society, giving, like receiving, is rarely obligatory, but there may be occasions when a person feels morally obliged to give certain gifts to others. For example, if a family member is in dire need of food, shelter, or even a kidney transplant (Murray 1987). Therefore, the obligation to give does still exist, albeit on certain occasions.

For a gift to be recognised as a gift, though, it is important for givers, as with receivers, to comply with certain implicit obligations when gifting. For example, a gift should be given freely (a gift that is imposed is not a gift), the value of the gift should not be exaggerated and it should not be given with any expectation or specifications of what is expected in return (Murray 1987, Godbout and Caille 2000). Monetizing the gift threatens to turn the gift into a commodity and the relationship into a commercial one, defeating the purpose of gift exchanges (Murray 1987).

Finally, in the modern gift, there is usually no ‘calculation’ between giver and receiver. Unlike in Mauss’s day, it is possible to ‘give without keeping scores’, particularly between friends and family, unless of course the purpose of the gift, as with competitive gift exchange, is to gain hold, power or domination over the recipient (Godbout and Caille 2000). In such instances, however, it is unlikely that the ‘gift’ would be viewed as such by either party. Most inanimate gifts are now not reciprocated in the same way that a loan is repaid and this illustrates that
some obligations, whilst present, are occasionally weaker than in The Gift (Mauss 1990).

1.9 Critical analysis

It is important not to get too embroiled in the praise of The Gift (Mauss 1990) as it could detract from the book’s shortcomings, of which there are several. Many of the problems, though, stem from the fact that Mauss (1990) developed his theory from historical documents and the research of other anthropologists. Therefore, as already stated, Mauss’s data were not only second hand but also, at times, limited (Godbout and Caille 2000). While most anthropologists are of the opinion that this did not have an overtly detrimental affect on the development of the gift theory in general (Godelier 1999, Godbout and Caille 2000), it is apparent that on some occasions, Mauss (1990) lacked sufficient empirical data to clarify certain issues that could have been used to develop his theory yet further. For example, Mauss (1990) admits to lacking enough insight into the rules of exchange and the compulsion to give, receive and reciprocate in such an obedient manner.

Also the theory of the gift does not provide answers to all our questions; on the contrary, it questions everything (Godbout and Caille 2000). For example, Mauss (1990) never provides a clear resolution of the relationship between ideas of obligation and spontaneity, between self-interest and the interest of others and to all of the ‘good reasons not to give’ (Godbout and Caille 2000). However, whether this is due to Mauss’s occasional lack of empirical data or simply his inability to clearly resolve certain issues is debatable.
There can be little doubt, though, that over three quarters of a century after Mauss's original publication, the enigma behind the gift persists (Godelier 1999). Even today, books and journal articles are published unabated, by some of the world's foremost anthropologists, discussing, debating and attempting to offer new insight into the concept of the gift. Levi-Strauss (1969) admits that the notion of the gift offers inexhaustible sociological analysis. Perhaps then, this failure of Mauss (1990) to provide all the answers to gifting could not be levelled as a serious criticism as the deliberations continue today. If 75 years of debate and publications cannot settle the matter once and for all, is it reasonable to have expected Mauss (1990) to do so in 100 pages?

The most significant criticism of Mauss (1990) relates to the actual gift theory itself. Mauss (1990), like many other anthropologists since, was fascinated by the intricacies of gift exchange and therefore sought to establish the underlying reasons for the perpetual cycle of gift and counter-gift. Mauss (1990), of course, maintained that giving, receiving and reciprocating were all performed obligatory. However, while it was relatively easy for Mauss (1990) to understand why one must give, since giving creates obligations, it was harder for him to understand why one must reciprocate (Godelier 1999).

Instead of giving, receiving and reciprocating being the equivalent of the other, in that each is equally necessary, reciprocation appeared to Mauss (1990) to be more important in practice and harder to grasp in theory than the other two (Godelier 1999). However, Mauss (1990) believed that he had found a solution to
this dilemma through the concept of ‘the spirit of the gift’, which he felt that, along with obligations, also helped to enforce the need to reciprocate. It is as if Mauss (1990) did not regard the existence of a rule of objective law (that is, obligations, which he felt governed the entire process) as a sufficient reason and felt the need to add a ‘religious or spiritual’ dimension (Godelier 1999). Levi-Strauss (1987) saw the reasoning and headed for it, castigating Mauss for having strayed from his analysis and having failed to apply the same method to all three steps (giving, receiving and reciprocating), which form a whole (Godelier 1999). Godelier (1999) adds, it seems that Mauss (1990) had momentarily forgotten to think as a scientist and let himself be mystified by an ‘indigenous theory’.

Mauss (1990) is also accused of taking the actual concept of hau, the ‘spirit of the gift’, out of context from its original historical Maori text. Whilst the religious content of the notion of hau is not in dispute, it is agreed that Mauss’s ‘excessively religious and spiritual’ interpretation of the notion of hau, as being the primary reason for reciprocation, is without foundation (Firth 1929, Sahlins 1972, Godelier 1999). Levi-Strauss (1987) maintains that the indigenous concepts of hau are in actual fact signifiers in themselves, devoid of any real meaning and thus susceptible to receiving any meaning at all. With regards to the concept of hau, it is believed that Mauss (1990) was not following true native beliefs but rather his own intellectualised interpretation of it (Firth 1929, Godelier 1999).

Mauss (1990) did not pay enough attention to the fact that in the societies explored, givers often retain some ownership rights of what they have given and
it is this, probably in conjunction with *hau*, that helps bring about reciprocation. However, instead of this ‘force of rights’, Mauss (1990) saw only a spiritual power, that of a soul inhabiting the gift, which controlled and defined its use and movement (Godelier 1999). Sahlins (1972) also adds that the threat of punishment by sorcery for failure to reciprocate probably did not come solely from the *hau* of the gift but also from the original givers frustrated by their failure to receive a return gift, a fact that Mauss (1990) does not explore properly in *The Gift*.

Once again, it must be questioned whether this misconstruction is due to the fact that Mauss (1990) never actually undertook the research on gifting himself. As he clearly found reciprocation the most complex of all the 3 stages in the exchange process, perhaps if he had been in the ‘field’ he could have probed his participants further to clarify these issues for him.

Mauss (1990) has also been widely criticised for his poor attempts to relate gifting to contemporary society. Mauss (1990), much like Levi-Strauss (1969) after him, could only really see gifting in birthday or Christmas presents, where it was a marginal vestige of what it had once been (Godbout and Caille 2000). However, if the gift only manifested itself today in such minor and marginal ways, there would not be much point in paying attention to it, except out of nostalgia or a predilection for folklore studies (Godbout and Caille 2000).

Admittedly, gifting as a form of exchange has now disappeared in favour of exchange for profit and, even though gifting is most apparent at birthdays and
Christmas, it is now just as relevant to contemporary societies as it was to ‘archaic’ ones.

Mauss’ other major attempt to relate gifting to modern day society, and which has also been significantly criticised, is to compare social security to gifting. In social security, Mauss (1990) saw a system comprised of givers (those who pay into the scheme through general taxation), receivers (the needy) and reciprocators (those who have previously received benefits but are now gainfully employed and so to pay into the scheme through taxation). He therefore concluded that social security was the equivalent of a modern day gift.

However, social security is not really a gift but rather a right in modern societies (Godbout and Caille 2000). For sure, social security and health insurance are an expression of solidarity but so too are a lot of things, and there the likeness ends (Douglas 1990). Social security is, of course, imposed and it is therefore the exact opposite of a voluntary gift (Godelier 1999, Godbout and Caille 2000). Taxpayers are legally obliged to contribute into it and those in need are legally entitled to receive from it. Therefore, neither contributors nor benefit recipients are likely to regard social security as a gift. Furthermore, the fact that social security contributions are compulsory means that such a state system would not necessarily shape people or reinforce an individual’s ‘altruistic tendencies’ (Godbout and Caille 2000).

Also, the money paid into social security by taxpayers is not intended or destined for a specific person. Likewise the recipient of social security knows that their
benefits have not come from a specific individual but from general taxes, which are distributed through the department of social security. As social security is an anonymous intermediary, as anonymous as money itself, it is totally divorced from social connections (Godbout and Caille 2000). Therefore, unlike in normal gift exchange, it is impossible for any social relationship to arise as a consequence of social security.

The final criticism of Mauss (1990) is that he fails to properly recognise or discuss the concept of the free gift. This is most probably because Mauss (1990) like many anthropologists, questions whether a truly free gift is ever really possible, as discussed earlier. However, Mauss (1990) never really makes his position clear in The Gift. He could have, and should have, spent some time explaining and justifying his position on this matter.

1.10 Conclusion

This chapter has critically explored the anthropological theory of gift exchange and its wide range of psychosocial implications, identified the strengths and weaknesses of the concept and demonstrated the relevance of the theory to both 'archaic' and contemporary societies. However, the concept of gifting has also been frequently linked to processes far more complex than the exchange of inanimate objects originally described by Mauss (1990), such as the exchange of human organs for transplantation. There is some anecdotal evidence and a surfeit of theoretical, though largely uncritical, healthcare literature that suggests that Mauss's (1990) gift theory may be of relevance to this process, particularly live transplantation. For example, Conrad and Murray (1999) and Fox and Swazey
(2002) suggest that the gift exchange theory may provide a useful framework for health professionals in helping to understand the behaviour of those involved in the live transplantation.

However, the concept has never been empirically tested in this situation and for this reason, we cannot yet have enough confidence in Mauss' (1990) theory to be able to use it to understand and describe the processes at work in live transplantation. There is, therefore, a need for credible research to be undertaken to establish if the anthropological theory of gift exchange is a relevant framework in helping to explore and understand the motivations to give, receive and reciprocate in those involved in the live transplantation process.
CHAPTER TWO: The concept of gifting in health care

2.1 Introduction

The previous chapter explored the origins and concept of the gift exchange theory. This chapter will explore when and why the notion of gifting has been associated with certain aspects of healthcare, such as blood and organ donation, and will conclude by discussing the intricacies and potential usefulness of this theory, as applied to the live transplantation process.

2.2 Gifting and healthcare

The concept of gifting has, for several decades, been theoretically associated with certain aspects of healthcare, particularly the donation of bodily fluids, tissue and organs. The theme of the gift in healthcare, though, probably first came to prominence in 1970 following the publication of Richard Titmus’ seminal work on blood donation in the UK and the USA (Godbout and Caille 2000).

Organ donation in particular has been described by health professionals, charitable organisations and procurement agencies as ‘the gift of life’, probably for several reasons. Firstly, the metaphor easily conveys to the public the good that comes from such procedure, whilst at the same time maintaining respect for organ donors, and the need to increase the number of organs available for transplantation (Gerrand 1994, Siminoff and Chillag 1999, Fox and Swazey 2002). Secondly, it directly reflects the principles of voluntarism and charitable altruism on which the entire donation system is based (Strathern 1992, Gerrand 1994, Lock 1995, Siminoff and Chillag 1999). Finally, the strategic use of the
metaphor by health professionals is seen as a way of ensuring that transplant patients are appreciative of their donated organ and are therefore more likely to take care of their general health and well being post-operatively (Siminoff and Chillag 1999).

Organ donation is often viewed as an exceptional act of gift giving, the ultimate act of human kindness (Gill and Hulatt 1999, Fox and Swazey 2002), since the selfless act of donation by one individual can transform and even save the life of another person who is seriously ill. When the focus is on the donated organ itself, then the intended sense of 'gift' is much easier to identify, as the organ is being given to someone in a similar way in which a present would be (Gerrand 1994). This sense of 'gift' as a present seems to capture more closely what is meant when the 'gift' metaphor is used in the context of organ donation (Gerrand 1994).

In terms of an exchange model, organ transplantation is sociologically and psychologically related to the dynamics of gift exchange as the process involves giving, receiving and reciprocating (Hilton and Starzomski 1994, Sque and Payne 1994, Fox and Swazey 2002). However, whilst organ transplantation is regarded as a gift, it will also be subject to the norms of giving, receiving and repaying with their attendant social, cultural and psychological functions and strains (Vernale and Packard 1990, Fox and Swazey 2002). For example, failure to meet any of the entwined expectations associated with gift exchange, such as failure to reciprocate, could produce dissonance that could affect donors, recipients and their families (Fox and Swazey 2002).
2.3 The exchange theory in organ donation

Although families of potential cadaver donors are free to choose whether or not to consent to multi-organ donation, Fox and Swazey (2002) maintain that, as in traditional gift exchange, many feel 'obliged to give'. Much of this pressure, they state, comes from the Christian beliefs, commonly found in Western societies, that giving to others is supremely good (Sque and Payne 1994, Siminoff and Chillag 1999, Fox and Swazey 2002). However, this hypothesis is not supported by the limited empirical evidence, which shows that relatives typically consent to donating their loved one's organs because they want to (citing reasons for doing so, such as, ensuring something meaningful comes from the tragedy and helping others in need) rather than because they feel obliged to (Bartuccci and Seller 1988, Gerrand 1994, Siminoff and Chillag 1999). Furthermore, no pressure is exerted on families of prospective multi-organ donors by health professionals in intensive care units (ITUs) to consent to donation and, despite organ donation being generally well supported in society, a recent national audit of all ITU deaths in the UK found that, on average, 40% of relatives refused to consent to multi-organ donation when offered the choice (UK Transplant 2006c).

However, as in Mauss's gift exchange theory, when it comes to receiving a human organ for transplantation, once a suitable organ is offered to a potential recipient then they are under considerable pressure to accept it (Siminoff and Chillag 1999, Fox and Swazey 2002). Although they can refuse to accept the organ if they wish to, it would be unwise and unlikely for them to do so as such a decision could result in a prolonged wait for another suitable organ to become available, deteriorating health and even death.
Cadaveric transplant recipients know that they have received their organ because another person has died. They are also aware that donor families have a right to refuse donation (Sque and Payne 1994). Therefore, when transplant recipients receive donated organs, it often sets up feelings of identification, indebtedness and special links of responsibility in them and their families (Fox and Swazey 2002). Consequently, as in traditional gift exchange, many transplant recipients want to reciprocate, in some way, the donor’s family for the ‘gift’ they have received. However, the psychological and moral obligations that recipients feel towards donors can be onerous because ‘the gift of life’ is of such extraordinary magnitude that it is inherently beyond reciprocation (Sque and Payne 1994, Smith 1998, Siminoff and Chillag 1999, Fox and Swazey 2002). There can, of course, be no reciprocation in economic sense because monetary reimbursement for human organs is outlawed in developed countries (Sque and Payne 1994, Godbout and Caille 2000).

Sque and Payne (1994) comment that the degree of responsibility, humility and indebtedness that giving and receiving an organ involves and the powerful influence that a transplanted organ can exert over the lives of those concerned can be a source of ‘tyranny’. This is probably exacerbated by the recipient’s desire, but inability, to properly ‘repay’ the donor’s family for such a priceless ‘gift’.

However, the inability to properly reciprocate the ‘gift’ received does not eliminate the impulse to attempt to repay. Just what constitutes appropriate reciprocation in these circumstances is debatable but many transplant recipients,
and their families, often send anonymous letters of thanks to donor families through the transplant coordinators in an attempt to deal with their sense of obligation and most find this an extremely satisfying act (Murray 1987, Sque and Payne 1994, Siminoff and Chillag 1999, Fox and Swazey 2002).

Bartucci and Seller (1988) explored donor families’ reactions to anonymous letters of thanks from organ recipients. Data were collected through questionnaires from a convenience sample of 39 donor families (29 of which were parents) from Ohio, USA who had received such correspondence post donation. The mean age of the participants was 45 years and the mean age of the donors at time of death was 26 years. All families, without exception, reported positive feelings regarding the letters they received (Bartucci and Seller 1988). One participant stated, “It feels good to know the recipients of the ‘gift of life’ appreciate what has been done for them” (p788). Another reported that the letter brought a sense of relief knowing that the transplant was a success and also a feeling of gratitude to the recipient for having written the beautiful letter of thanks, saying “It brought happiness, it was uplifting knowing that something good had come from this tragedy” (p789) (Bartucci and Seller 1988).

Although the sample group is small and unrepresentative, the study does provide some credibility to the relevance of the gift framework within organ donation. For example, even though donor families in this study may well have consented to donation with no reciprocal intention, they reported that they wanted and needed information concerning the organ recipient. Such information assured the families that ‘the gift’ was appreciated and useful to the recipient (Bartucci and
Seller 1988). This reaction corresponds with the obligation to receive and reciprocate in the gift exchange theory (Siminoff and Chillag 1999).

Clayville (1999) investigated how meeting the recipient of a loved one's organ affected the lives of donor families and collected data, through semi-structured interviews, from five purposely selected donor families (eight individuals, three men and five women) from the Pacific Northwest, USA. Two interviews were conducted with parents who had lost a child, one with a mother who had lost her child, one with a mother and son who had lost their daughter/sister and one was a wife who had lost her husband. All participants were white and each had lost a loved one within one to five years prior to the study.

All eight participants identified positive ways in which their lives had been influenced by the meeting and noted how the experience helped them manage the pain of losing a family member (Clayville 1999). One participant stated “part of the healing comes from knowing that the recipient and their family are extremely grateful and this affected us all in a positive way” (p83). Another stated, “The recipient is very thankful, which I appreciate” (p84).

As with Bartucci and Seller's (1988) research, transplant recipients in Clayville's study (1999) clearly wanted to show their appreciation to the donor families and all donor families interviewed, clearly valued this gesture. Although the gift exchange theory was not empirically tested, or even discussed, by Clayville (1999), her findings, like those of Bartucci and Seller (1988), demonstrate that there are elements of gifting behaviour in her study population. For example, a
need on the behalf of recipients to attempt to reciprocate the ‘gift’ received by thanking the donor family, and the donor families’ desire and gratitude for such a response.

There are, however, limitations to this study. The focus of the research, as with Bartucci and Seller’s (1988) study, is entirely on donor families. Neither study explored the experiences of recipients and their families. Therefore, it is unclear how they feel about such issues post transplant. Research, of a longitudinal nature, is also required to establish how beneficial such meetings are to donor and recipient families. For example, there is a possibility that one party may become overly dependent on, or even obsessed, with the other.

Some transplant recipients seek other means to deal with their feelings of obligation, such as becoming members of transplant patient support groups (Siminoff and Chillag 1999). Although there is no empirical evidence to explain why, some recipients might behave in this way perhaps because, as Godbout and Caille (2000) demonstrated with AA members, there is a desire by some transplant recipients to ‘give something back’ after having received so much.

2.4 ‘Gatekeepers’

Organ donation is not a ‘pure’ system of gift exchange but a mixed system because there are a variety of professional intermediaries, referred to as ‘gatekeepers’, involved in the process besides the giver and receiver (Godbout and Caille 2000). These ‘gatekeepers’ (health professionals) play an important role in regulating the entire donation process (See Figure 3). They screen for
Figure 3. Gift exchange theory applied to the organ transplantation process

Adapted from Sque and Payne (1994).

*Gatekeeping*; This refers to health care professionals
*The object of reciprocity*; In this instance it may be letters of thanks or other expressions of gratitude relayed to the donor’s family, via the transplant coordinator.
biologically acceptable organs and decide which organs are retrieved and to whom they are given (Sque and Payne 1994). They also control the amount of information that the donor families receive about the recipient and vice versa (Vemale and Packard 1990) and ensure that, if letters are exchanged by donor and recipient families, anonymity is maintained unless or until both parties agree otherwise. This social control mechanism helps ensure that neither party becomes overtly demanding or obsessed with the other (Fox and Swazey 2002).

2.5 Gifting in other aspects of healthcare

The gift exchange paradigm has also been theoretically referred to in other aspects of healthcare besides organ donation, such as blood, ova and bone marrow donation. The concept of gifting was first associated with blood donation in 1970 by Richard Titmus. Titmus (1997) used a variety of research to compare and contrast voluntary blood donation in England and Wales with the largely paid donation system that existed at that time in the USA in order to establish which approach provided the most effective, efficient and safest means of collecting and distributing human blood. At the time of the book's original 1970 publication, Titmus (1997) discovered that human blood cost 5 – 15 times more in America than in Britain, 30% of collected blood was wasted in the USA compared with just 2% in Britain and, more strikingly, American blood was about four times more likely than British blood to infect its recipients with hepatitis (the main threat from donated blood at that time) (Oakley and Ashton 1997). However Titmus has been justly criticised for too crudely assuming that paid/voluntary donation was the crucial factor explaining the efficiency of
different donation systems and for playing down the importance of the sound practice in blood banking (Oakley and Ashton 1997).

Titmus found that paid donation systems such as those in the USA tended to attract infected blood from poverty-stricken donors, whose honesty was often questionable, because the motives they relied on were morally inferior (Oakley 1997). Conversely, he found that voluntary blood donors used a moral vocabulary to explain their reasons for giving, such as a desire to help others. In the British donation system, Titmus (1997) also saw that unpaid donors gave blood in a voluntary, disinterested manner and regarded donation not as an obligation to the state, nor as a business transaction, but as a gift (Godbout and Caille 2000). However, when human blood is bought and sold, as was prevalent in the US at the time of the Titmus (1997) study, its status changed from a gift to a commodity. Finally, in support of the gift analogy, Titmus (1997) found that some voluntary donors gave blood because they, or members of their immediate family, had previously received a blood transfusion. Titmus (1997) quite reasonably saw this as an act of reciprocation.

More recently, Royse and Doochin (1995) conducted research in order to gain a greater understanding of factors associated with blood donation and repeated blood donation. Questionnaires were distributed to 500 randomly selected blood donors and 500 purposively selected ‘multi-gallon donors’ (those who had donated 5 gallons of blood, or more) from a pool of 35000 known blood donors in central Kentucky, USA. Two hundred and eighty three (57%) questionnaires were returned by the multi-gallon donors and 105 (21%) by the randomly
selected donors. Royse and Doochin (1995) found that external factors (such as, social pressure and awareness of need) played an important role in motivating newer blood donors whereas intrinsic factors (for example, the personal satisfaction of giving – a form of reciprocation; Godbout and Caille 2000) were more important in the motivation of committed blood donors. Royse and Doochin (1995) also found, in support of Titmus and the gift framework, that a significant proportion of participants (40% of the random sample, 47% of the multi-gallon sample) had a personal relationship with a blood recipient, and the committed blood donors whose friend or family member had received blood donated more units than their counterparts. This finding was interpreted as evidence for the importance of reciprocity and responsibility; in fact Royse and Doochin encouraged the increased use of the message that donors have a moral obligation to replace units of blood that family members or friends receive (Gardner and Cacioppo 1995).

However, whilst the donation of human blood has many similarities to gifting, it is also fundamentally different from the ‘archaic gift’ because it is voluntary, carries with it no obligation to reciprocate (although many recipients or members of their family do), is not destined for a specific individual and is handled by an intermediary (the blood transfusion service) (Godbout and Caille 2000). Therefore, there can be no relationship between giver and receiver as a consequence of the ‘gift’ or no personal expression of gratitude or other sentiments, such as reciprocation, on behalf of the recipient (Titmus 1997).
Using participant observation and semi-structured interviews, Lessor (1993) explored the experiences of 14 separate cases of sisters involved in ovarian egg donation in one university infertility centre in the USA. Lessor (1993) discovered that all sisters donated their eggs out of love for their sister and because they felt that it was the ‘right thing to do’. Many referred to their activity as ‘giving the gift’ (Lessor 1993). All recipients, and their husbands, expressed a sense of immense gratitude at their sisters’ gesture and reported that they didn’t quite know how they could ever really repay their sisters for what they had done for them. In searching for an appropriate reciprocal gesture, one recipient and her husband gave the sister a gold watch after she had donated and the recipient had become pregnant (Lessor 1993). Egg donors also commonly viewed the act of donation as one of the most significant ‘highlights’ of their lives (satisfaction of giving, a non-material form of reciprocation; Godbout and Caille 2000). Most sisters also reported that the relationship with their sister had improved considerably since donation.

In a longitudinal, two year ethnographic study of anonymous ova donors and recipients in London, Konrad (1999) found that donors gave in order to help others and, as in Lessor’s (1993) research, reported that donated ovas constituted ‘gifts of life’ to others. All recipients (although no numbers are given) reported feelings of immense gratitude towards their anonymous donor and, consequently, all felt that a special bond now existed between them, although anonymity ensured that there could never be a formal relationship between the two parties.
In a USA study of 343 unrelated bone marrow donors, Switzer et al (1997) found that common reasons for donating marrow were exchange related motives (awareness of benefits, desire to help others), empathy related motives (putting themselves in the place of the recipient), positive feeling motives (satisfaction of giving – a form of reciprocation; Godbout and Caille 2000) and past-experience motives (experience with an ill family member). As in cadaveric organ donation, unrelated bone marrow recipients commonly report significant feelings of gratitude and indebtedness towards their donor and many send anonymous letters of thanks through the donor registry in an attempt to deal with their sense of obligation (Smith 1998). However, again, anonymity ensures that there can be no formal relationship between donor and recipient.

2.6 Cadaveric organ donation: is it really analogous with gifting?

Whilst there are many similarities between cadaveric organ donation and traditional gift exchange, there are also some fundamental differences, which propounds the question of whether the process constitutes a ‘true gift’ (Caplan 1986, Strathern 1992, Gerrand 1994, Koenig and Hogle 1995, Godbout and Caille 2000). Significant differences include the lack of freedom of giving and receiving related to ‘gatekeeping’ factors in the procurement process (Conrad and Murray 1999). That is, a person cannot choose who to give an organ to. Also for a gift to truly be a gift then it has to be the givers to give (Gerrand 1994). Yet in cadaveric donation, it is the donors’ families who consent to the act of giving and not the donors, even if they carried a donor card, because the donors are dead.
Furthermore, organ recipients cannot personally express their gratitude to the donors, because they are dead, or even to the donor families, because current procurement procedures ensure that they remain anonymous. Although, as already discussed, many recipients express their gratitude to donor families anonymously through the transplant coordinator. Finally, the donation cannot be the basis for any relationship between the two parties, since in the case of cadaver donation, it can only take place because the donor has died (Gerrand 1994). Therefore, despite the similarities between gifting and the act of multi-organ donation, these significant differences suggest that cadaveric donations cannot constitute a ‘true gift’ in the Maussian sense.

Largely because of these issues, Gerrand (1994) postulates that multi-organ donation possibly has more in common with an act of charity than an act of gifting. He arrives at this conclusion by explaining that the salient features of acts of charity (that they are supererogatory, should be performed voluntarily and be motivated by altruism) are the same features of most voluntary organ procurement campaigns.

Siminoff and Chillag (1999) suggest that the use of the gift metaphor in organ donation may be unhelpful to transplant recipients and their families as it could add to their feelings of guilt and indebtedness. But is it the mere use of the gift metaphor that evokes these feelings in transplant recipients, or are such emotions evidence, however anecdotal, that the gift framework is relevant within the context of organ donation? If this is the case then, far from wanting to abandon the use of the metaphor in organ donation, the gift exchange theory could provide
health professionals with a framework for understanding the experiences of families involved in the organ donation process.

2.7 Live organ transplantation

Despite there being a plethora of information available regarding the concept of gifting within organ donation, the theory has only really been considered from the perspective of cadaveric transplantation, probably because this approach provides the majority of human organs for transplantation in the western world. However, there is a greater degree of similarity between the act of live related donation and the act of giving a gift than between cadaver organ donation and gift giving (Gerrand 1994).

In live organ donation, the kidney 'belongs' to potential donors and it is, therefore, theirs to give away if they so wish. Unlike in multi-organ donation, there is also a pre-existing relationship, either through consanguinity, marriage or, in some cases, close friendship, between the potential donor and the recipient. Consequently, there is a potential for some family members to feel compelled to donate a kidney to a loved one simply because they are related (Harvey 1990, Tabok 1994, Lamb 1996). As Fox and Swazey (2002) state:

'Where a person is faced with a seriously ill relative whose life could possibly be saved by a live organ donation from a family member the Maussian “obligation to give” is maximised' (p. 9).

However, if a prospective donor is induced or coerced in some way to donate, then the donation would probably not be sufficiently voluntary to be called a gift (Gerrand 1994). Conversely, some live donors may have ulterior motives for donating, such as a desire to gain emotional control or power over the recipient
(Argles 1997). Such donors could then exploit the situation to their advantage by constantly referring to the sacrifice they have made for the recipient, thus perpetuating the recipient's sense of indebtedness. In this instance, it is dubious whether the organ would be regarded as a gift by either party (Gerrand 1994). However, Hilton and Starzomski (1994) maintain that most live donors probably give their kidneys simply because they want to help a loved one. Where there is no such coercion, demands or extortion, the act of living organ donation does seem to be analogous to giving a gift because the giver wants to benefit the recipient, has acted freely and nothing is expected in return for the donation (Gerrand 1994).

It is possible, though, that potential live transplant recipients would be reluctant to accept a kidney from a loved one out of concern for their health and well-being (Schwietzer et al 2003). However, it is also likely that if both parties want the transplant to proceed then the recipient would gratefully accept the kidney.

In a longitudinal, two year qualitative study of 10 Canadian families' (donors and recipients) experiences of the live donation process, Hilton and Starzomski (1994) found that, although live donors gave with no implied reciprocal intention, many recipients (though they fail to quantify the extent) indicated a sense of obligation towards the donors for their actions.

However, even though most live donors may not expect any reciprocation of a mercantile kind, as in traditional gift exchange, many do (often implicitly) expect something back from the recipient, such as an expression of gratitude or the
expectation that the recipient will assume responsibility for maintaining a healthy lifestyle post-donation (Conrad and Murray 1999). In a study of related kidney donors, Simmons et al (1987) found that when recipients did not express what the donors considered to be a reasonable amount of gratitude (although it is unclear in the paper what constitutes ‘reasonable’), they felt angry and used. Nonetheless, multiple studies have found that virtually all live donors find the donating experience positive, worthwhile and fulfilling (Simmons et al 1987, Fehrman-Ekholm et al 2000, Stothers et al 2005).

Simmons et al (1987) also found, given the potential disruption to family relationships posed by the dramatic ‘gift of life’, that only 7% (n=9) of donors and recipients reported that their relationship had been made more difficult by the transplant. Much more common was a feeling of being brought more closely together. One way this was accomplished, given the unreturnable nature of the gift, was for the donor to minimise the recipient’s obligation to show gratitude (Murray 1987). It is, however, possible that the bond forged between the live donor and recipient might be so intense that it could undermine relationships with other family members and consequently have a detrimental effect on family dynamics (Fox and Swazey 2002).

2.8 Critical analysis

Whilst much has been written about gifting within the context of organ transplantation the relevance of the theory to this process has never been empirically tested. Most, if not all, of the literature to date remains theoretical in nature and from the perspective of cadaveric donation, despite the significant
differences already discussed. Very little empirical or theoretical information is available from the perspective of live transplantation, despite the more significant similarities.

However, although gifting is often not explicitly referred to in many of the studies reviewed, the collective findings suggest that organ transplantation, particularly live transplantation, appears to relate closely to the dynamics of this concept. Yet none of the reviewed studies, including that by Titmus (1997), empirically tested the relevance of the gift theory. Furthermore, most studies, explored patient’s experiences retrospectively and from only one perspective; either that of the donor (e.g., reasons for giving) or, to a lesser extent, the recipient (e.g., how they feel about receiving) but rarely both collectively. Therefore, in order to better understand the live transplantation process, there is a need for longitudinal research to be undertaken that can illuminate the experiences, at pre and post transplant, of both parties involved in live kidney transplantation.

Also, although the label of gift has been frequently applied to organ transplantation, the concept is usually referred to in an unthinking, uncritical, manner and has rarely been conceptualised by health professionals in a way that yields insights into its broader medical and psychosocial significance (Fox and Swazey 2002). This proposed study will therefore aim to establish if the gift exchange theory is applicable in the context of live kidney transplantation and, if so, what is the usefulness of this framework to health professionals. For example, Sque and Payne (1994) and Conrad and Murray (1999) claim that Mauss’s theory
is probably most useful in exploring the motivations involved in the obligations to give, receive and reciprocate. The framework may help to illuminate the relationships that arise as a consequence of the donation. For example, how does the recipient feel about the donor’s action? Does the recipient want, in some way, to reciprocate in order to demonstrate their appreciation?

The gift theory may also highlight the strains and stresses that the donor, recipient and their families are likely to experience pre and post transplant, thus helping to direct practical, policy and educational strategies to ensure that health professionals are better equipped to support those involved in the process and to facilitate decision-making at such a complex time (Sque and Payne 1994). The study could provide health professionals with a greater insight into the clients’ experience and the practical, psychological and emotional strains of the whole transplant process. Consequently, this may help to ensure that transplant personnel deliver the highest standard of effective and efficient, holistic care and support to those concerned pre and post transplant.

2.9 Conclusion

In this chapter, the anthropological theory of gift exchange has been explored within the context of healthcare, specifically focusing on the potential relevance and usefulness of this theory to the live transplantation process. In the next chapter, organ transplantation within the UK will be discussed, focusing on live kidney transplantation and the experience of the process from the perspectives of donors, recipients and their families.
CHAPTER THREE: The live kidney transplantation experience

3.1 Introduction

In the previous chapter, the concept of gifting was explored in relation to healthcare, particularly focusing on organ donation and live kidney transplantation. In this chapter, organ transplantation within the UK will be explored, focusing on the need for and benefits of live kidney transplantation, common problems with live transplants, patient and family experiences of the actual process and the need for further research.

3.2 The need for and benefits of live kidney transplants

Although renal transplantation is recognised as the treatment of choice for most patients with ESRD, the demand for all transplantable organs, particularly kidneys, far exceeds availability (BTS/RA 2000, Hariharan 2000, Cabrer et al 2003, Wafa et al 2004). Throughout the 1990s, the number of cadaver donors in the UK has steadily declined (largely due to a fall in death rates from road traffic accidents and intracranial haemorrhages) whilst, at the same time, the number of people waiting for organ transplants has steadily increased (Lumsdaine et al 1999, BTS/RA 2000, Calder and Chang 2004, UK Transplant 2006a) (See figure 4).

However, live kidney transplants offer an excellent solution to this problem due to the resultant decrease in the number of patients competing for the limited number of cadaver kidneys. They also help to avoid the long and unpredictable
wait for a cadaver kidney and pre-emptive transplantation is often possible (i.e., a transplant is performed when the patient still has some remaining renal function) thereby reducing, or in some cases even avoiding, the time spent on dialysis (Fangmann et al 1999, BTS/RA 2000, Olbrisch et al 2001). The procedure also allows for careful preparation and tissue typing of donor and recipient and for surgery to be scheduled at an optimal time. Therefore, patient and graft survival rates for living related (genetically related) and living unrelated (emotionally related) kidney transplants are superior to cadaver kidney transplants (Terasaki et al 1995, Johnson et al 1997, Foss et al 1998, Fangmann et al 1999, Lumsdaine et al 1999, BTS/RA 2000, Olbrisch et al 2001, Cabrdr et al 2003, Wafa et al 2004, UK Transplant 2006f).

Fehrman-Ekholm et al (2000) explored the views and assessed the subjective health of 370 live kidney donors who had donated a kidney between 1964 and 1995 in Stockholm, Sweden. Data were collected retrospectively through questionnaires, which explored the experiences and views of donation and also included a standardized health form (SF-36), which measures health on 8 different scales (e.g., physical functioning and general health perception). According to the SF-36, the overall subjective health scores of the donors were higher in all 8 health scales than the age and gender adjusted general Swedish population (Fehrman-Ekholm et al 2000). Furthermore, almost 99% (n=365) of live donors reported that they were happy to have donated and did not regret their decision to donate (Fehrman-Ekholm et al 2000).

Similar findings have been reported in other European and American retrospective studies (Jacobs et al 1998, Johnson et al 1999, Schweitzer et al
However, these findings have been questioned by some researchers because of their retrospective nature (some data collected up to 30 years after the actual act of donation). They may, therefore, be subject to some bias, such as the distortion of perceptions over time (Schover et al 1997). Due to the rigorous pre-transplant assessment criteria and process, live donors are also generally in good health and probably already have an above average quality of life before donation (Biller-Andorno 2002). There is also the potential for social desirability associated with live transplantation and, therefore, some donors may want to interpret the transplant as a success and report an especially good quality of life as the expected or desired outcome (Biller-Andorno 2002).

Nevertheless, the collective findings from multiple studies are positive and there is no empirical evidence to support the above hypotheses. Consequently, the reported physical and psychological benefits, coupled with an ever-increasing transplant waiting list, means that live kidney transplantation represents an effective and reliable intervention for most patients with ESRD.

3.3 Problems associated with live transplantation

Despite the well-reported benefits of live kidney transplants, the procedure is associated with physical and psychosocial risks that may affect donors, recipients and their families.

3.3.1 Physical risks

The physical risks associated with living kidney donation can be divided into the early post operative risks and the long-term risks of life with one kidney. The
reported mortality rates following live kidney donation is approximately 0.02% - 0.06% (1 death per 4800 - 1600 donors respectively), with the most common causes of death being pulmonary embolus, hepatitis and cardiac events (e.g., myocardial infarction) (Duraj et al 1995, Vietch 1996, Johnson et al 1997, Lumsdaine et al 1999, BTS/RA 2000, Ross 2000, Matas et al 2003, The Amsterdam Forum 2005).

Accurate post operative morbidity rates following live kidney donation are difficult to establish because there is a relative dearth of follow up data and because variations often exist in the precise definition of specific complications (e.g., what constitutes a ‘wound problem’?). However, reported post operative morbidity rates vary between 8% and 48%, with a mean overall complication rate of approximately 32% (Johnson et al 1997, BTS/RA 2000). Yet most complications are regarded as minor (e.g., urinary tract infections) with only around 2-4% regarded as major complications (e.g., pneumonia and pulmonary embolus) (Weiland et al 1984, Duraj et al 1995, BTS/RA 2000, Fehrman-Ekholm et al 2001, Matas et al 2003, The Amsterdam Forum 2005).

It has also been postulated that the long-term risks for live kidney donors includes an increased incidence of hypertension and ESRD and a decreased life expectancy. However, there is no convincing empirical evidence available to support any of these hypotheses (Weiland et al 1984, Kasiske et al 1995, BTS/RA 2000, Fehrman-Ekholm et al 2001, The Amsterdam Forum 2004). In fact, available evidence indicates that there is little long term physical risk to a healthy donor after unilateral nephrectomy (The Amsterdam Forum 2005).
Therefore, based on the best available medical evidence, it would appear that the physical risks associated with live kidney donation are relatively low, but real nonetheless. More detailed longitudinal evidence and agreed levels of reportage of complications are required, though, to help more accurately clarify the short and long term physical risks of live kidney donation.

3.3.2 Psychosocial issues

There are several potential psychosocial problems associated with live transplantation. For example, as the person with ESRD may face deteriorating health and may even die whilst waiting for a kidney transplant, it is possible that some family members may feel compelled, either by their own sense of moral duty or by the recipient and their family, to volunteer to become a live donor (Conrad and Murray 1999, Olbrisch et al 2001, Fox and Swazey 2002). There is also the possibility that some family members may volunteer to donate because they are seen as the ‘black sheep’ of the family, and may therefore see donation as an opportunity to gain family approval and appreciation (Kemph et al 1969, Russell and Jacob 1993, Jacobs et al 1998). Because of these issues, it has been questioned whether prospective live donors can truly give voluntary, informed consent to donate (Lamb 1996, Olbrisch et al 2001).

A small scale, UK study using a quota sample of 86 healthy adult participants (43 men/43 women) revealed that whilst 76% (n=65) of participants were prepared to become a multi-organ donor on death, 93% (n=80) were prepared to donate a kidney to a close relative (e.g., son/daughter) (Gill and Hulatt 1999). However, these findings should be treated cautiously as the sample was small, non-randomly selected and recruited from only one demographic area in South
Wales. Furthermore, hypothetical situations are often somewhat different to reality and opinions expressed may not, therefore, actually reflect what these participants would actually do.

Nevertheless, more participants in this study were prepared to donate a kidney to a relative than become a cadaver donor. The exact reasons for this are unclear but it could be postulated that such an act would be performed out of care and concern for a loved one. It has been suggested, though, that in such situations, some family members may feel emotionally compelled to donate (Harvey 1990, Tabok 1994). However, multiple studies have shown that most live donors do not feel pressured to donate and are usually able to make their decisions quickly and easily (Higgerson and Bulecheck 1982, Morris et al 1987, Karrfelt et al 1998, Jacobs et al 1998, Fehrman-Ekholm et al 2000, Cabrer et al 2003, Schwietzer et al 2003, Stothers et al 2005).

In what is now regarded as seminal work, Simmons et al (1987) explored the decision making process among a cohort of 130 live donors who donated a kidney between 1970-1973 and 1978-1980 in Minnesota, USA. Data were collected retrospectively through questionnaires and interviews. The authors found that donors’ decision making fell into one of three decision making models; moral/straightforward (decision made immediately with no apparent period of deliberation), deliberation (decision made after a period of consideration) and postponement (no conscious decision made, the donor is either ruled out for medical reasons or becomes a donor when compatibility established). Of the 130 participants, 96 (74%) used the moral/straightforward
decision model, 33 (25%) used the deliberative model and only 1 (1%) used the postponement model (Simmons et al 1987). Although this study is now two decades old and based in only one US transplant centre, the findings have since been supported by multiple studies (e.g., Schover et al 1997, Karrfelt et al 1998, Eggeling 1999a, b, 2000, Cabrera et al 2003, Schweitzer et al 2003, Stothers et al 2005) that show that the decision to donate is relatively straightforward and easy to make for most live donors.

Despite the apparent willingness to donate by most donors, the donor's welfare throughout the transplantation process is paramount. Therefore, to ensure that prospective live donors make rational, informed decisions regarding donation, it is important that they are given adequate time and support to consider their decision, are provided with sufficient information regarding the procedure and potential risks and are provided with an opportunity to discuss their concerns openly and honestly (Sadler 1973, Argles 1997, Nolan 1999, Abecassis et al 2000, Burroughs et al 2003, Stothers et al 2005). No pressure should be exerted on prospective donors by the transplant team and they should be aware that they are free to withdraw from the process at any time, without prejudice.

If prospective donors do decide to withdraw, for whatever reason(s), the medical and/or individual reasons for not proceeding should be kept confidential (The Amsterdam Forum 2004). Some transplant units will provide prospective donors with a valid 'medical excuse' for not proceeding with the transplant, if they feel they cannot go ahead with it. Whilst the morality of providing such an 'alibi' is, perhaps, questionable, it is important that, if the situation arises, medical issues
should not be falsified that could have later ramifications for the patient (Abecassis et al 2000).

Despite the ease with which most donors make the decision to donate, many have common concerns about donating, such as pain and the effect of donation on future health (Calder and Chang 2004). Hiller et al (1998) conducted a retrospective telephone survey with a cohort of 61 live donors who had donated a kidney between 1995 and 1997 in Baltimore, USA, to identify concerns that donors had regarding the procedure. The study found that 15 live donors had no concerns but 46 (75%) had health or socio-economic concerns that they had to address before deciding to donate. The most common concerns were the potential effects on future health (n=24), length of hospitalisation (n=6), pain (n=4), the length of time off work (n=18), ability to return to the same level of activities (n=16) and the ability to care for children and the family while recuperating (n=6).

However, donors were not asked if their concerns had delayed or prolonged the time to donate or if (and how) the concerns had affected their decision to donate (Hiller et al 1998). Furthermore, the study did not explore how the donors overcame these concerns, since all donated. For example, were their concerns identified and adequately addressed by the transplant teams concerned?

It has been reported that around 75% of all potential live donors are unsuitable to donate, usually on medical grounds, leaving just a small percentage of prospective donors available for eventual transplantation (Trevitt et al 2001,
Calder and Chang 2004). It is essential, therefore, that any concerns prospective donors have regarding donation are properly recognized and addressed by the transplant team, to ensure that such issues do not have a negative impact on the donors' eventual decision.

Recipients are also subject to potential pressure when making decisions about live transplantation. Many prospective recipients are often reluctant to accept a kidney from a loved one, even when offered, because of concern for the potential donors' health and well being, or other issues, such as the donor's age (e.g., if they are a minor) or their family responsibilities (Hilton and Starzomski 1994, Murray and Conrad 1999, Olbrisch et al 2001, Franklin and Crombie 2003).

Murray and Conrad (1999) conducted a prospective, mixed method study in a Mid-Atlantic State, USA, to explore the perceptions of kidney transplants in a random sample of 115 untransplanted dialysis patients. Of those interested in transplantation (n=62), 60% (n=37) preferred the cadaveric option and only 5% (n=3) were interested in live related transplants, because of their concern for their loved ones. However, none of the participants had discussed the option with their family and most were unaware of the high success rates of live transplantation.

In some circumstances, prospective recipients may also feel that the kidney is being given 'conditionally' by the donor, for example, to gain power or control over them. In this situation, recipients may reject the offer of a transplant if they feel it will leave them overtly 'indebted' to the donor. Many recipients, therefore, require a great deal of help, information and support from health professionals,
the donor and other family members before deciding to proceed with live transplantation (Hilton and Starzomski 1994, Murray and Conrad 1999, Schweitzer et al 2003). Recipients' experiences of live transplantation have, however, been subject to very little research. Consequently, relatively little is known about this area.

There are also reports of psychosocial problems, such as depression and family conflict, for a small number of live donors (Russell and Jacob 1993, Nolan 1999). Morris et al (1987) conducted a small retrospective study, using questionnaires and semi-structured interviews, with a cohort of 12 live donors who had donated a kidney between 1980 and 1985 in a single Australian centre, to explore donation experiences and to identify factors that might be associated with complicated outcomes. Although all the donors were generally positive about donating, it was found that 5 donors developed psychosocial complications post donation, such as depression, anxiety and, in one case, marital breakdown (this participant also unsuccessfully attempted suicide through drug overdose) (Morris et al 1987). The authors also found that 4 of the 5 donors with complications were without a stable relationship (e.g., with a spouse), or perceived their social support to be inadequate. Consequently, they argue that this lack of social support may have made the development of post-operative psychological morbidity more likely in this group. However, the study, which is now two decades old, was based in only one newly developing Australian transplant unit and this, together with a small sample group, limits the ability to generalise the findings to the wider transplant population.
The most serious incidence of psychological sequelae following live kidney donation is reported by Weizer et al (1989) who discuss two cases of suicide by related kidney donors in Israel following graft rejection and death of the organ recipients. Both donors were male, in their late 40s and immigrants (from Romania and Russia) with no previous psychiatric history, although both were clinically depressed at the time they committed suicide. One donor donated to his brother, the other to his son. No empirical and little clinical psychological data were recorded prior to the incidents, therefore the precise reasons for the suicides are unclear. However, the authors attribute the suicides to the unbearable grief and depression brought on by the failure of the transplant and the eventual death of the recipients. It cannot be known, however, whether the death of a loved one would have triggered the suicides, regardless of the transplant failures.

Graft rejection or failure is relatively rare in live kidney transplants in the UK. The average one year graft survival rate for live kidney transplants is currently 93% (UK Transplant 2006f). Unfortunately, a small proportion of recipients will inevitably experience rejection or failure of their transplant. If and when it does occur, it can be devastating for recipients, as well as donors, and can cause profound depression and grief like reactions (Baines and Jindal 2002). In light of this, it is widely agreed that there is a need for psychological support and follow up care for donors, recipients and their families who undergo the trauma of graft failure (Weizer et al 1989, Russell and Jacob 1993).

Despite these issues, live transplantation is generally a positive experience for most donors and recipients, with few serious problems reported (Burroughs et al
2003). However, research indicates that problems are more likely to occur if donors or recipients develop major complications (e.g., graft rejection) post transplant, donors are ambivalent about donating, expectations of the transplant are unrealistically high, donors or recipients feel poorly informed about the procedure and their recovery and/or they feel poorly supported by health professionals or their families (Simmons et al 1987, Morris et al 1987, Jacobs et al 1998, Johnson et al 1999, Schweitzer et al 2003). It is, therefore, essential that prospective live donors and recipients are properly prepared for transplantation and provided with adequate care, support and information by the transplant team before and after transplantation.

3.3.3 The potential impact of transplantation on the family

The whole transplant process is potentially very emotive and, consequently, may have a significant impact on the lives of other close family members. For example, spouses may be very concerned about their loved one's health because of transplantation (Bratton and Griffin 1994, Hilton and Starzomski 1994, Karrfelt 1998, Nolan 1999). If the potential recipient is a child and both parents are able to donate, the question arises of who should donate. Live transplants may also have financial implications for donors and their immediate families. Time off work is often required during the work up period and, some donors are unable to claim full sickness benefits post-operatively because they voluntarily entered into a major surgical procedure that is not for their personal benefit.

There is also the potential for family conflict to arise if the donor's spouse, or significant others, believe that they are putting the well being of the recipient
before their own nuclear family (Hirvas et al 1976, Russell and Jacob 1993, Bratton and Griffin 1994, Fox and Swazey 2002, Crombie and Franklin 2006). It appears, though, that family conflict is more likely to arise if the recipient is not part of the donor’s immediate family (Simmons et al 1971, Higgerson and Bulechek 1982, Hilton and Starzomski 1994). However, whilst in some cases family dynamics may suffer as a consequence of transplantation, research has shown that for most families, the relationships between donor, recipient and their families generally improves, or, at the very least, remains unchanged post transplantation (Higgerson and Bulechek 1982, Simmons et al 1987, Hilton and Starzomski 1994, Karrfelt et al 1998, Jacobs et al 1998, Burroughs et al 2003).

3.4 Transplant service issues

Research has shown that the potential risks associated with live transplantation are, in fact, relatively small and generally only affect a small proportion of patients (BTS/RA 2000, The Amsterdam Forum 2005). Furthermore, live transplantation is generally viewed as a positive experience by most donors and recipients (Burroughs et al 2003). Nonetheless, the welfare of patients involved in the process is paramount. It is therefore essential that potential problems are recognised and properly addressed by the transplant team, to help ensure that decisions to become involved in live transplantation are made on an informed basis.

All transplant units offer routine pre-transplant assessments to evaluate, amongst other things, the physical and, occasionally, psychological health of the donor and recipient. Psychological assessments are often used to explore, amongst
other things, relationships, reasons for donating, expectations, concerns and preparedness for transplantation (Calder and Chang 2004). Whilst the routine use of psychological assessments in live transplantation has been advocated by many health professionals (Olbrisch et al 2001), their use and value to the process has never been conclusively established. Given the potential effects on other family members (e.g., spouses), it is also important to support them throughout the transplant process, whenever and wherever possible (Morris et al 1987).

Although a number of serious decisions confront the family considering a live transplant, no clear guidelines are available to help them through the experience (Hilton and Starzomski 1994). Knowing more about the experiences of families involved in live transplantation would, therefore, assist health professionals to provide the necessary care and support to these families. An extensive search of the literature, however, reveals that, despite the excellent results of live transplants, very few studies have paid any attention to the experiences and perspectives of those involved in the process. This lack of empirical evidence means that it is unclear whether the standard holistic care currently provided to those involved in live transplantation adequately meets their needs. The little, relevant evidence available comes mainly from a qualitative, pilot study by Eggeling (1999a), who explored the experiences of the transplantation process with 13 live kidney donors, and their immediate families, in South West Thames, UK.

Eggeling’s (1999a) study suggests that many live donors and their immediate families frequently feel let down by the health care service provided to them.
Eggeling (1999a) reports that many donors felt undervalued by the service because transplant personnel usually made contact with them via the recipient and not with them directly. Some donors also reported that too many consultations with health professionals involved shared appointments with the recipient, which they felt affected confidentiality and their ability to talk honestly about worries or concerns. However, not all transplant centres operate a shared appointment system. For example, the transplant centre in this current study allocates different physicians to the donor and recipient to avoid potential conflicts of interest and ensure confidentiality.

Eggeling (1999a) also found that family conflict can occasionally arise if spouses feel excluded from the donor’s decision-making process. Most donors and their families claimed that the transplant service failed to adequately meet their need for information, education, advice and support, which left many feeling dismayed and uncertain. These findings are supported by a small (10 families), longitudinal, qualitative Canadian study (Hilton and Starzomski 1994) and a two-year retrospective audit of 24 live donor families in London, UK (Burnapp 1999). Hilton and Starzomski (1994) and Burnapp (1999) report that some donor families (although no actual numbers are given) specifically complained that written and verbal information regarding post-operative recovery was inadequate and that they were also very concerned with the lack of follow up care and support from the transplant team. Lack of follow up care and attention was also identified as a donor concern in a British study by Crombie and Franklin (2006).
If families are not adequately supported by health professionals throughout the transplant process then, besides failing to meet their personal needs, this may affect their ability to offer help and support to the donor and/or recipient. As discussed earlier, the consequences of a lack of support from the family could, potentially, increase the likelihood of physical and psychological morbidity in live donors (Morris et al 1987). Therefore, it is important for health professionals to involve close family members (e.g., spouses) in decisions regarding treatment options whenever possible, and to provide them with adequate support and information to help ensure that they do not feel excluded, that their own needs are met, the likelihood of family conflict is reduced and that they are better able to support the donor and/or the recipient (Simmons et al 1987, Hilton and Starzomski 1994, Veitch 1996, Eggeling 1999a: 1999b, Murray and Conrad 1999).

However, whilst the findings from Eggeling's (1999a) study give some insight into donor experiences of transplantation and transplant service issues, the lack of methodological detail makes it difficult to assess their validity. Furthermore, the study only explored the experiences of donors and their families; it did not evaluate the experiences of recipients or their families. Therefore, there is a need for further research to explore if the service provided to all relevant individuals (not just donors) involved in live transplantation adequately meets their needs.

There is, therefore, a need to illuminate the experiences of such families to help health professionals provide appropriate, person-centred care. The resultant improved understanding of the experiences of clients involved in live transplants
and of the transplantation process will help to inform healthcare practice. The
current study could, therefore, improve how health professionals treat, care and
support families involved in live transplantation. It is envisaged that, in
collaboration with the transplant team in South West England, the findings from
this aspect of the study could be constructively used to explore the potential
implications for future clinical practice. The findings are anticipated to have
important policy and practical implications, such as training and educational
issues, for health professionals working closely with transplant patients and their
families.

3.5 Summary

The reviewed studies have revealed the importance of, and need for, exploring
patient’s experiences throughout the live transplant process, but there are a
limited number of appropriate studies that have explored these perspectives.
Furthermore, most relevant studies have only explored the experiences of live
kidney donors and, occasionally, their families. An extensive literature search
revealed that very few studies have explored the experiences of recipients and
their families or the combined experiences of donors and recipients. Also most
published studies are retrospective in nature. There are few longitudinal studies
that explore the experiences of families as they progress through the
transplantation process.

Live kidney transplantation has increased slowly but steadily in the UK over the
last decade and now accounts for around 29% of all transplanted kidneys per
annum (UK Transplant 2006b) (see figure 5).
However, due to the shortage of transplantable kidneys, the well reported physical and psychological benefits of live transplants and the relatively low rate of associated problems, it is highly likely that the number of live kidney transplants performed in the UK will increase significantly over the next decade to rates comparable to Scandinavian countries, where the extensive use of grafts from live donors has resulted in a relatively stable waiting list for cadaveric transplants (Foss et al 1998, BTS/RA 2000).

As the number of live kidney transplants increases, so too does the need to explore and better understand the process and experiences of those families concerned, to help guide the provision of care, information, advice and support.

3.6 Conclusion

This chapter has explored the supply-demand mismatch problem for transplantable organs, the need for and benefits (physical and psychosocial) of live kidney transplants, physical and psychosocial problems associated with the procedure and the experiences of families involved in the process. The need for and importance of further research has also been identified. The next chapter will identify the research questions and the research process used to address them.
CHAPTER FOUR: The research process

4.1 Introduction

In the previous chapter, patient and family experiences throughout the live transplantation process were explored and the need for, and potential benefits of, further research identified. In this chapter, the research questions and research methods are discussed.

4.2 The aims of the research

This study was undertaken to further explore and understand the experiences of donors, recipients and their families throughout the live transplantation process. Therefore, following a critical review of the literature, the following research questions were formulated:

➢ What are the experiences of donors, recipients and their ‘significant others’ throughout the live transplantation process?

➢ Is the anthropological theory of ‘gift exchange’ a relevant framework to explore and understand the live kidney transplantation process?

➢ How may a theoretically informed, in-depth insight into these experiences be used to inform and develop future research and clinical practice?

4.3 Research approach

When selecting a research approach, qualitative or quantitative, it has to be determined which is best able to reliably answer the research question(s) (Anderson 1991, Morse and Field 1996, Cormack and Benton 2000, McPherson and Lord 2000, Silverman 2000). The value of a study is significantly influenced by the suitability of the research approach used and the manner in which the research is conducted. It is, therefore, essential to select the most appropriate research approach for the study. Using an inappropriate approach may result in
dubious, weak, unreliable and possibly invalid findings (Morse and Field 1996, Robinson 2002).

When selecting an appropriate approach, it is useful to have a general knowledge of a variety of research methods and therefore the ability to consider a range of possibilities, eliminate those that are not appropriate and select one which is best suited to the study (Cormack 2000, Silverman 2000, Robinson 2002).

Due to an existing understanding of research methods, and the research questions posed, I initially felt that a qualitative research approach was required, with interviews as the method of data collection. However, I also realised that I needed to further explore this matter to extend my understanding of research methods and to establish whether my initial decision was both justified and correct.

4.4 Quantitative and qualitative research approaches
Quantitative research (particularly in the form of the randomised controlled trial; RCT) has traditionally dominated much of healthcare research (Polit and Beck 2005). However, qualitative approaches to research are now being recognised, particularly by nurses, as equally important to health care enquiry. Both approaches have a place in nursing research because they are each capable of addressing different research questions and therefore contributing to different aspects of nursing practice (Britten 1999, Polit and Beck 2005).
For example, quantitative research provides quantified answers to research problems and, although there are exceptions, is commonly associated with positivistic, experimental research (Pope and Mays 1995). Quantitative research methods, such as surveys and RCTs, are frequently used to establish cause and effect relationships, the incidence of disease, to test experimental hypotheses, determine the effectiveness of medical interventions or treatments (e.g., new drug therapies), or for determining the opinions, attitudes or practices of a large population (e.g., how people intend to vote) (Pope and Mays 1995, Greenhalgh and Taylor 1997, Silverman 2000, Porter 2000, Maggs-Rapport 2001).

Conversely, qualitative research does not seek to provide quantified answers to research questions and tends to be associated with more naturalistic types of research (Pope and Mays 1995). Qualitative research approaches are commonly used to explore, interpret, or obtain a deeper understanding of certain aspects of human beliefs or behaviour, such as people’s personal experiences and perspectives (Greenhalgh and Taylor 1997, Cutcliffe and McKenna 1999, Silverman 2000). Such approaches are therefore ideally suited to research where little is already known or understood, or to access areas that, because of their personal or unique nature, are generally not amenable to quantitative approaches (Britten 1999, Pope and Mays 1999, Sadala and Adorno 2002).

However, neither approach to research is necessarily superior to the other. The appropriateness of the chosen approach depends on its ability to address the research problem. For example, if the purpose of a particular research study was to explore the effectiveness of a new anti-rejection drug on graft survival rates in
kidney transplant recipients, then a quantitative approach would probably be the most desirable. A randomised controlled trial would probably be used to provide quantified answers to the research problem, with study participants being randomly grouped into either receiving the new trial drug or an already established drug or placebo.

However, if the purpose of the proposed study was to explore the experiences of complying with an anti-rejection drug regime in post transplant recipients, then a qualitative approach would probably be desirable. The primary reason being that the researcher would be seeking to obtain rich, deep meaningful information through, for example, interviews, to develop a greater understanding of the effects of such a regime on the patient, their life and, possibly that of their families. In such a study:

'The investigator is really seeking to understand how people make sense of an experience that is complex, interpersonal and dynamic. It would be possible to investigate this problem with structured instruments, but it is likely that the investigator would never really come to understand the process that is the focus of the inquiry' (Polit and Hungler 1993, p.325).

The purpose of the proposed study was to explore the experiences of live kidney donors, recipients and their significant others throughout the live transplantation process, and to develop an understanding of these experiences in relation to the formulated theoretical framework (the gift theory). I believed that the experiences of each participant would probably be unique and possibly influenced by a variety of factors; such as their individual beliefs and values, the progression and effects of the illness on recipients and their families, the relationship between donors and recipients (and their respective family members), feelings regarding the act of donation (e.g., if organs were given
'conditionally' or if the donation caused internal family conflict) and other issues, such as financial concerns. I also felt that the feelings of each participant would probably change over time, depending on factors such as the success or failure of the transplant, post-operative recovery, effects of the transplant on recipients' lives, the provision of service from health professionals and family dynamics post-transplantation.

There was (and still is) a dearth of empirical research in this area. Whilst some relevant studies were found that explored the experiences of live kidney donors, in contrast, very few could be found that explored the experiences of recipients or the combined experiences of donors and recipients. The study could not therefore concentrate on specific aspects of donor or recipient experiences, or test any preformulated hypotheses.

I therefore felt that a quantitative research approach would not be suitable for this study and, consequently, concluded that the research would be best conducted using qualitative methods. The reason for favouring this approach was because, as Silverman (2000) comments, a qualitative approach can provide a 'deeper' understanding of social phenomenon, such as interpreting and understanding the clients' world, than would normally be obtained from a purely quantitative approach.

I believed that interviews were the most appropriate method of data collection, as they were more likely to reveal rich, deep information regarding feelings and views of the transplant process, care provision and any subsequent issues. Whilst
questionnaires, for example, may have allowed for a larger sample (although only an additional 10 families were available for inclusion in the study during the recruitment period), the data obtained would probably not have provided as much insight into the thoughts, feelings and experiences of the participants.

4.5 Qualitative research approaches

There are many different types of qualitative approaches but the most common used in nursing research are ethnography, phenomenology and grounded theory (Liehr and Marcus 1994, Ploeg 1999, Silverman 2000, Robinson 2002). Each are capable of answering different research questions and are derived from different academic disciplines. Consequently, the philosophical and ideological foundations of each approach differ, the methods used in each approach are distinct and the results provide a different perspective of the phenomenon (Ploeg 1999, Silverman 2000, Robinson 2002) (see table 1).

Table 1.

Common qualitative research approaches used in nursing research

<table>
<thead>
<tr>
<th>Research Approach</th>
<th>Origins</th>
<th>Domain of enquiry</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grounded theory</td>
<td>Sociology</td>
<td>Using a systematic set of procedures to arrive at theory about basic social process</td>
</tr>
<tr>
<td>Ethnography</td>
<td>Anthropology</td>
<td>Exploring values, beliefs, descriptions and perspectives of cultural groups or subgroups</td>
</tr>
<tr>
<td>Phenomenology</td>
<td>Philosophy</td>
<td>Exploring the lived experiences of participants</td>
</tr>
</tbody>
</table>

4.6 Which qualitative approach?

Given the research questions, the possible qualitative approaches that were initially considered were grounded theory, ethnography and phenomenology. However, further extensive reading was subsequently undertaken to select the most appropriate research approach and eliminate the least appropriate.

4.6.1 Grounded theory

Grounded theory was developed by Glaser and Strauss in the 1960’s and provides a mechanism for generating theories about human behaviour (Morse and Field 1996). The data analysis process in grounded theory, as in most qualitative research, is ongoing, in that emerging hypotheses and theories, which account for behaviour variations, are constantly formulated and reviewed during data collection (Parahoo 1997). However, the major premise of this approach is that all theories and hypotheses are supposed to emerge from the data rather than from a body of predetermined theory, either in the form of assumptions by the researcher or, for example, in the form of a conceptual framework to guide the study (Pope et al 1999, Barbour 2001, Wengraf 2001, Robinson 2002). Polit and Hungler (1993) comment that:

‘The grounded theory method is primarily concerned with generating categories, theories and hypotheses rather than testing them’ (p.333).

Consequently, even though there is some debate about how and when grounded theory should be used, even amongst Glaser and Strauss (Morse and Field 1996), the approach itself is generally best suited to studies where little or nothing is yet known, either empirically or theoretically, about the study phenomenon.
Therefore, because of the formulated research questions and theoretical framework, together with the critical, empirical and theoretical insight into the live kidney transplantation process provided in the literature review, I felt that this approach would not be suitable for this particular study.

### 4.6.2 Ethnography

The ethnographic approach originates from social anthropology and its main purpose is to learn and understand about a culture from the people who actually live in that culture. Anthropologists have traditionally conducted ethnographic studies amongst non-westernised cultures. However, by contrast, non-anthropologists, such as sociologist or health professionals, are more likely to study particular milieux or ‘subcultures’ in their own society (Silverman 2000). In healthcare research, for example, this may involve examining the beliefs and practises of delineated communities such as staff working in operating theatres or groups of individuals experiencing a common illness such as cancer or AIDS (Morse and Field 1996).

An ethnographic study demands extensive periods of time ‘in the field’, often up to 1-2 years, and total immersion in the research participants’ way of life, in order to fully learn about their views, beliefs and perspectives (Maggs-Rapport 2001). There is, though, some debate in healthcare research as to what length of time is required ‘in the field’ for a study to constitute an ethnography. Whilst 2 years of sustained fieldwork may not be required in healthcare research, a certain period of continuous contact with participants, performing repeated interviews and participant observation is generally expected.
Consequently, because of this, and the potential constraints of the setting and participants (some of whom would also be subject to an invasive surgical procedure that would require periods of hospitalisation and recuperation), I felt that a true ethnographic study, involving sustained contact with several families, would be too imposing and potentially intrusive and would, therefore, not be possible.

4.6.3 Phenomenology

Phenomenology emerged from philosophy around the late 19th century (Anderson 1991, Morse and Field 1996, Ploeg 1999). The purpose of the phenomenological approach is to accurately describe the 'lived experiences' of people. Crotty (1996) states:

'The purpose of studying experiences is to understand them - their nature, their meaning, their essential structure. A phenomenological method will help uncover meaning and provide an interpretation of the meaning of human experiences in its situated context. In short phenomenology seeks to render lived experiences intelligible' (p. 13).

In phenomenological research, data are normally collected through in-depth interviews, occasionally combined with participant observation, with people who are living the experience being explored (Liehr and Marcus 1994). During this process, researchers should allow participants to talk as freely as possible about the topic in question, although researcher guidance may be required to develop the interview, to help ensure that participants describe their experiences in their own words. Participants should not be guided by rigid interview questions or the researcher's own agenda.
As the focus of phenomenology is on lived experiences, the approach is often well suited to the study of participants’ experiences of a particular illness and the care they receive (Crotty 1996, Parahoo 1997). Therefore, given the research questions and the philosophy and purpose of phenomenology, I initially felt that this approach would be the most appropriate for conducting my study.

However, heterogeneity exists within phenomenology and researchers using this approach must, therefore, distinguish between the two main schools of thought. Consequently, to develop a greater understanding of phenomenology and to ensure that I chose the most appropriate approach for my study, I undertook further critical reading of phenomenological literature.

4.7 The phenomenological approach

Whilst phenomenology is a philosophical tradition or movement, highly diverse and internally differentiated, in itself, it does not constitute a method of data collection and analysis; that is, it does not uniquely specify particular research techniques (Atkinson 1995). However, a research endeavour informed by phenomenology does refer to a set of disciplining understandings that inform its scope, focus and direction and, as such, it has definite implications for the character of data collection and analysis (Toders and Wheeler 2001).

Consequently, although phenomenology is essentially a philosophy that has subsequently been adapted as a research approach, it is now frequently referred to as both a philosophy and a research approach, in which the main objective is to examine and describe phenomena as they are consciously experienced.
4.8 Nursing research and phenomenology

The phenomenological approach has recently grown in popularity in nursing research. This trend is evidenced by an increase in publications of phenomenological research studies in the nursing literature (Beck 1994a). The exact reasons for this increase in popularity are unclear, but a number of contributory factors seem likely.

Firstly, it has been argued that phenomenology represents a break from positivistic research, which has largely dominated medically orientated research for many years, but is not always congruent with the discipline of nursing, which describes its philosophy as holistic and interactive and its epistemology as knowledge based on experiencing human persons (Anderson 1991, Beck 1994a). Secondly, nurse researchers often study phenomena that cannot easily be explored through medical, psychological or sociological frameworks. For example, research into pain in healthcare has traditionally focused on the physical, social and psychological aspects of pain but has rarely managed to capture the individualized nature of pain and its unique human experience for different individuals (Todres and Wheeler 2001).

The phenomenological approach can therefore provide nurses with an insight into the personal experiences of patients and their families and can therefore provide a greater understanding of important healthcare issues such as 'what is it
like to live with a certain illness’, or ‘what are their experiences of service delivery’?

Phenomenology and clinical nursing practice are also similar in a number of ways. Both emphasise observing, interviewing and interacting with clients so that a deeper understanding of the client’s experience can be grasped (Beck 1994a). Beck (1994a) adds:

‘Because nursing is primarily a social act between nurse and client, the phenomenological perspective can help increase nurses’ understanding of their clients by entering into their life world’ (p 508).

There have, however, been a number of salient and sometimes damning critiques of how phenomenological research has been conducted, particularly in nursing (Caelli 2001). For example, many nurse researchers have failed to clarify, or have simply misconstrued, the specific meanings of the phenomenological terminology used in their work, such as ‘essence’ and ‘bracketing’ (Crotty 1996, Paley 1997).

Some research is also based on philosophical misinterpretations (Lowes and Prowse 2001). For example, some nurse researchers often refer to their research as phenomenological, yet fail to make a clear distinction as to what specific branch of phenomenology is being used and why. As the philosophical and methodological underpinnings of each main branch varies, it does have a significant bearing on the research study. Koch (1995) maintains that nurse researchers should appraise the philosophical underpinnings of the methodologies they pursue. This is a difficult task for researchers engaging a new mode of enquiry because it requires that they fully comprehend the
intricacies of phenomenology before they can do so (Caelli 2001). However, if a piece of research is to be logical, coherent, rigorous and methodologically and philosophically sound then these distinctions must be made.

4.9 Phenomenological approaches

Two main schools of thought have developed within the phenomenological movement and, over the years, each has been subject to multiple interpretations and modifications (Anderson 1991, Morse and Field 1996, Holloway and Wheeler 2002). Caelli (2001) states:

'Each different philosophical approach grew out of a particular view of what it means to be human and to be in the world and thus carries with it assumptions about the nature of being human and the nature of the world in which we live' (p. 276).

Although there are commonalities between these traditions there are also significant philosophical and associated methodological differences. These differences can, potentially, make it confusing and problematic for researchers considering undertaking a phenomenological approach, particularly those, like me, who have never used this method before. This problem is also exacerbated by the fact that, despite the voluminous publications on the topic, there are few concrete directions for undertaking phenomenological research. This situation has primarily arisen because of the particular and unique nature of phenomenology and its derivation from, and inextricable involvement in, the philosophical movement from which it arose (Caelli 2001).

It is, however, essential for researchers to select the most appropriate phenomenological approach for their study, if it is to be as rigorous as possible
(Holloway and Wheeler 2002). But to do this, one must first develop a clear understanding of, and appreciate the distinction between, the complex philosophy of the two major traditions – that is, Husserlian phenomenology and Heideggerian hermeneutics (Koch 1995, Paley 1997, Caelli 2001).

I will therefore explore the two main schools of phenomenological thought and establish whether or not they are relevant to my study.

4.10 Husserlian transcendental phenomenology

Edmund Husserl (1859-1938) is widely acknowledged to have pioneered phenomenology (Holloway and Wheeler 2002, Sadala and Adorno 2002). Husserl’s fundamental concern was an epistemological one, that is, the search for the foundations of knowledge; a philosophy referred to as transcendental phenomenology (Koch 1995, Todres and Wheeler 2001).

Husserl’s phenomenology was the culmination of the Cartesian tradition (mind/body duality), and came to mean the study of phenomena as they appear through the consciousness (Koch 1995). Central to Husserl’s approach was the fundamental recognition of human experience ('lived experience' or 'life-world') as the ultimate ground and meaning of knowledge (Koch 1995, Sadala and Adorno 2002). Husserl claimed that these lived experiences are not always easily accessible because they are experiences that are often ‘taken for granted’. That is, they are events or occurrences that we live through, yet to which we often give little constructive thought.
The task of Husserlian phenomenology is to explore these ‘lived’ or ‘taken for granted’ experiences in order to make them intelligible and discover their true meaning (Koch 1995, Todres and Wheeler 2001, Sadala and Adorno 2002).

Koch (1995) states:

‘Husserl wanted to bring to light the ultimate structures of the consciousness (essences) and to critically evaluate the role these structures play in determining the sense of it all’ (p.828).

There are three central concepts that are fundamental to Husserlian phenomenology; intentionality, essences and phenomenological reduction (bracketing) (Koch 1995).

Husserl believed that people directed their minds (consciousness) towards ‘objects’ (a generic term that can refer to things in the external world, concepts, essences...anything) and this directedness is called ‘intentionality’ (Koch 1995, Paley 1997). The consciousness simultaneously shapes the object and is shaped by it (Crotty 1996). Crotty (1996) adds:

‘Intentionality means that human experience always points to something beyond itself. It is essentially related to the phenomenon – to the object of experience, to what is experienced’ (p. 40).

Husserl hoped that his phenomenological approach would reveal the ultimate structures (essences) of consciousness (Koch 1995). Cognitivists postulate that a person’s knowledge, understanding, intentions and actions originate in the mind, which is the only source of meaning and interpretation (Benner and Wrubel 1989). If this is true then, in theory, essences can be isolated and studied (Thompson et al 1989).
Central to transcendental philosophy is the concept of ‘bracketing’, which is, perhaps, one of the most contentious and frequently debated notions within Husserlian phenomenology. It has been argued that researchers bring a certain amount of ‘intellectual baggage’, in the form of prior knowledge, beliefs and preconceived ideas, to the research they undertake (Crotty 1996). Such preconceptions and presuppositions may colour the interpretations researchers make about the phenomenon under investigation (e.g., sickness, illness or caring) and may also be imposed on the research process (Crotty 1996, Todres and Wheeler 2001).

Husserl’s solution to this dilemma was the concept of ‘bracketing’. Bracketing involves researchers identifying and ‘suspending’ their preconceived ideas and assumptions about the phenomenon under study so as to keep their beliefs separate from those revealed by the participants (Koch 1995, Crotty 1996, Sadala and Adorno 2002). Through this process, the layers of meaning provided by a researcher’s knowledge and interpretation are preserved and set aside so that the phenomena can be seen as they are, not as they are reflected through preconceptions (Beck 1994a, LoBiondo-Wood and Haber 1994). That is, participants’ experiences are presented in terms that are personally significant to them.

Bracketing is said to defend the validity or objectivity of interpretation against the self-interest of the researcher (Koch 1995, Paley 1997). Caelli (2001) argues that without bracketing, the search for essential structures of a phenomenon is not possible.
However, the concept of bracketing raises many issues. For example, it has to be questioned whether absolute bracketing is ever really possible? Beck (1994a) maintains that, whilst it is impossible for a researcher to be completely free of bias, in reflection on the experience being studied, it is possible to control it. However, Parahoo (1997) states that:

‘Bracketing is not easy to achieve as it is not possible for people to totally suspend their presuppositions nor to account for all of them, especially if they are not aware that they are using them’ (p. 154).

Another problematic issue that has to be addressed is precisely who, in the research process, should bracket? Caelli (2001) maintains that in phenomenological research, where both the participants and researchers seek to describe primordial (‘primitive’) experiences, surely it must be all those involved in the research process. However, the concept of bracketing is difficult to grasp and to achieve for neophyte, and even experienced, researchers, so how realistic is it to expect participants to fully understand and undertake bracketing? Accepting that even experienced phenomenological researchers have difficulty reaching a common interpretation of bracketing, it is perhaps unrealistic to expect participants to achieve an understanding of this concept and difficult to see how bracketing can be fully operationalised in research contexts (Lowes and Prowse 2001).

It has also been suggested that bracketing belongs within the domain of positivistic science as the concept implies that an objective view of the world is possible (Harper and Hartman 1997, Mulhall 1997).
4.11 Heideggerian hermeneutics

Martin Heidegger (1889-1976) was a student of Husserl and led the development of hermeneutical phenomenology (Todres and Wheeler 2001). Whilst Husserl’s philosophy focused on ‘the lived experience’, Heidegger’s focused on the ‘interpretation’ of the experience. Heidegger focused on what it means to understand, and he sought to clarify the conditions in which understanding takes place (Koch 1995, Todres and Wheeler 2001).

The origins of hermeneutics, however, lie in the interpretation of written documents, particularly scriptural passages, but it has since come to be associated with the interpretation of the whole of human existence (‘world as text’) not just written documents (Koch 1996, Todres and Wheeler 2001).

Heidegger’s philosophy contains two essential, inextricably intertwined notions; the historicality of understanding and the hermeneutic circle, which comprises of the concepts of background, pre-understanding, co-constitution and, Heidegger’s fundamental philosophical premise, interpretation (Koch 1995).

‘Background’ is what society and culture gives a person from birth and presents a way of understanding the world (Koch 1995). This understanding helps to determine what is true or real for us. Heidegger’s ‘background’ comprises of a multitude of factors (e.g., cultural, personal and historical) and, as such, cannot be made completely explicit (Koch 1995).
'Pre-understanding' describes the meaning and organisation of a culture (including languages and practices) that are already in the world before we understand (Koch 1995). It is not something that we can simply ignore, eliminate, or bracket (Koch 1995) because it is already with us in the world; it is what we already understand, experience and live (Todres and Wheeler 2001).

Another way to understand this process is to see the person and their world as co-constituting each other (Heidegger 1962). 'Co-constitutionality' is a philosophical notion that assumes that there is a perpetual unity between a person and the world:

'This means being constructed by the world in which we live and at the same time constructing this world from our own experience and background' (Koch 1995: p831).

Heidegger (1962) maintains that nothing can be encountered without reference to our background understanding. That is, every encounter entails an interpretation based on our background (Leonard 1989). Benner (1985) identifies this notion of background preunderstanding as one of the major distinctions between Heideggerian hermeneutics and Husserlian phenomenology. Whereas Husserlian phenomenologists believe in a suspension of presuppositions, Heideggerian phenomenologists propose that all knowledge originates from people who are already in the world and seeking to understand other people who are already in the world (Lowes and Prowse 2001, Maggs-Rapport 2001). This concept of 'being in the world' is believed by Spiegelberg (1982) to be possibly the most important characteristic of hermeneutic phenomenology (Lowes and Prowse 2001).
Therefore, when trying to develop an understanding of another person’s world, Heideggerians presuppose prior understanding on the part of the interpreter, refuting the notion that it is possible to bracket one’s ‘being-in-the-world’ in the process of philosophical inquiry (Walters 1995, Lowes 2000):

'Researchers subscribing to Heideggerian philosophy acknowledge that they can only interpret something according to their own beliefs, experiences and preconceptions, which are a legitimate part of the research process and should not be left out. This, the phenomenological interview, based on the philosophy of Heidegger, incorporates the researcher’s preconceptions in the generation of data (i.e., researchers participate in co-creating data). Indeed, this is a defining characteristic of Heideggerian phenomenological interview and research process' (Lowes and Prowse 2001, p.474).

However, for Heidegger, all claims to understanding are made from existing provisional assumptions (or fore-structures), which cannot be eliminated but may be corrected and modified in the process of experience and reflection (Koch 1995, Todres and Wheeler 2001). This process is referred to as the ‘hermeneutic circle’. Todres and Wheeler (2001) state:

'This circular, hermeneutic process has no absolute starting point nor any obvious final end point to our understanding, we are always ‘on the way’. There can thus be no non-positional understanding of anything; understanding is always situated and never absolute’ (p4).

The hermeneutic circle is a methodological process in which there is a constant search for understanding and meaning of the data and involves continual movement between parts and the whole of the text being analysed (Polit and Beck 2005). This process involves constant reading and re-reading of data to search for and identify emerging themes.
4.12 Approach to the study

Having explored the philosophical underpinnings of Husserlian phenomenology and Heideggerian hermeneutics, I felt that Husserlian transcendental phenomenology was incongruent with my own beliefs about humankind or the construction of qualitative research. My fundamental concern with Husserl’s philosophy related to the premise that researcher objectivity could somehow be obtained through the practice of ‘bracketing’. I felt that, given my clinical (particularly in caring for cadaver donors and their families) and academic background (reading, writing and publishing on various aspects of organ donation), and what I would therefore bring to the research process, bracketing would simply not be achievable or desirable.

I took the view of Koch (1996) (in reference to Heideggerian philosophy) that just as participants bring their own background perspectives and pre-reflective understandings of the world, formed by their own experiences, so do we as clinicians and researchers to the research that we undertake. I felt that these perspectives and understandings could not be disregarded, forgotten or bracketed. I therefore believed that, because of our historicality, when attempting to interpret and understand participants’ experiences, we simply cannot objectively separate ourselves from our backgrounds. Koch (1995) maintains that these values, rather than getting in the way, make the research more meaningful to its consumers and help to assist researchers, influenced by Heideggerian hermeneutics, in co-creating interview data with participants.
As my beliefs about people and qualitative research are more consistent with the philosophy of Heideggerian hermeneutics, the study was therefore guided by this interpretative approach.

4.13 Study design

The design of this study involved collecting data from participants through a series of three tape-recorded, semi-structured interviews. The first interviews were conducted pre-transplant and the subsequent two interviews at 3 months and 10 months post-transplant. Most interviews were conducted in the participants’ homes although some were performed, at the participant’s request and for their convenience, in a private room at the regional transplant centre in South-West England.

All interviews were conducted separately with each participant (not as a group) at the specified pre and post transplant intervals. The reasons for this approach were largely based on issues discussed earlier in the literature review. For example, in Eggeling’s (1999b) qualitative study of live donor and family experiences of transplantation issues and service provision, it was found that there were some instances of spousal disharmony, between donors and their partners, when partners felt excluded from the decision-making process. The same study also revealed that some donors expressed concern about shared hospital appointments with recipients which, they complained, often affected their ability to talk openly and honestly with health professionals (Eggeling 1999b).
Consequently, I felt that there might be occasions where some participants would feel uncomfortable about disclosing certain information, for example, of a personal or sensitive nature, in front of their partners, particularly if the prospective donor and recipient were married to each other or where the impending transplant had caused some family conflict. Therefore, to avoid such situations and help create an environment where participants felt free to talk openly and honestly, I felt that it would be more appropriate to interview each participant separately.

The initial pre transplant interviews were conducted after the prospective live donor had undergone a pre-transplant angiography, which was their final medical investigation in the pre-transplant assessment process. This cautious approach ensured that time (theirs and mine) and resources were utilised appropriately because, at this stage, withdrawal from the live transplantation process, for medical reasons, was less likely. I also believed that, at this later stage, all participants would probably have a little more experience of the transplantation process and of service provision and would, therefore, be in a better position to offer a greater insight into these issues than perhaps if they were interviewed earlier on in the process.

This initial interview was conducted as near to the date of the transplant as was practically possible. However, because of family issues, holidays, dialysis regimes, hospital appointments and illnesses, all interviews were arranged at dates that were most convenient for the participants. Therefore, pre-transplant interviews were conducted as near as 3 days pre-transplant and, in one instance,
due to the postponement of the original transplant date because of in-dwelling line sepsis (which I only discovered when I arrived to conduct the interview that had been set up several days previously when the original transplant date was still in place), as late as several weeks before transplantation.

The framework of the initial interviews merely explored several themes related to the research questions (see appendix 5). For example, participants were asked to describe their experiences of the transplantation process, healthcare service provision and relationship issues related to the impending act of donation. I undertook a thematic approach to the interviews, as opposed to a series of heavily structured questions, because I felt that it would provide some guidance to participants (to help ensure that the data gathered were relevant to the research questions) but would also allow them to describe their experiences in their own words.

Parahoo (1997) states:

‘Structured interviews can impose the researcher’s perspective on the participants. The areas covered are chosen by the researcher and therefore largely reflect what they think is important. Phenomenology interviews allow participants to talk freely, although the researcher may try to prevent them straying to other topics’ (p. 286).

The semi-structured approach also allows openness to changes of sequence and forms of questions in order to clarify or follow up the answers given by participants (Kvale 1996).

The first post transplant interviews were conducted 3 months post-transplant. It was originally thought that these interviews would be conducted at
approximately 5 months post transplant. However, on further discussion with my supervisors, it was agreed that participants’ experiences at 5 months post-transplant would probably be very similar to experiences at 10 months. For this first post-transplant interview, I wanted sufficient time to have elapsed for participants to have recovered sufficiently from the immediate post operative phase of the transplant, but still be able to reflect somewhat on the process relatively close to the actual act of transplantation when key issues would still be relatively fresh in their minds. It was therefore agreed that a suitable time to conduct this first follow up interview was at 3 months post-transplant.

As with the pre-transplant interviews, these first follow up interviews also explored several key themes related to the research questions, such as participants’ experiences of post transplant issues, such as follow up service and relationships issues (see appendix 5). As and when appropriate, some specific follow up questions were also asked, in relation to particular issues raised by participants in their first pre-transplant interviews.

The final interview was conducted at 10 months post-transplant. The purpose of these final interviews was to, again, explore participants’ feelings regarding issues such as follow up service, which according to Hilton and Starzomski (1994), Burnap (1999) and Eggeling (1999b), is an area for concern for many donors and their families, and to explore if, given some further time, the relationship between participants had been affected by the act of transplantation. Besides the thematic approach to this interview, once again further specific
questions were asked, as and when appropriate, in accordance to issues raised in the two previous interviews (see appendix 5).

All interviews lasted in the region of 20-60 minutes.

4.14 Repeated interviews

The reason for conducting ongoing interviews pre and post transplant was to attempt to more accurately explore participants' feelings about issues such as the transplant, relationship issues and service provision throughout the transplantation process. Longitudinal study designs often prove to be costly, particularly in terms of time and effort, and participants' feelings about the interviewer at the initial interview may, positively or negatively, affect the data generated at later interviews (Kvale 1996, Wengraf 2001). However, the reasons for favouring repeated interviews was because the approach can provide increased depth of responses from participants, early trends can be investigated, potential changes in relationships can be explored and any changes in the variables of interest over time can be assessed (LoBiondo-Wood and Haber 1998).

4.15 The research sample

The general purpose of sampling in rigorous quantitative research is to study a representative subsection of a precisely defined population to be able to make inferences about the whole population (Silverman 2000). Consequently, quantitative sample groups tend to be large, randomised and representative, so that the results reflect, on average, the condition of the population from which
the sample was drawn (LoBiondo-Wood and Haber 1994, Greehalgh and Taylor 1997).

In qualitative research, however, the interest is not in the ‘average view’ of a population but on gaining an in-depth understanding of the experiences of particular individuals or groups of individuals (Greehalgh and Taylor 1997). Therefore, sample sizes in qualitative research are not predetermined by any rigid rules and tend to be small because of the large volume of verbal data that must be analysed and because this type of design tends to emphasise intensive and prolonged contact with subjects (LoBiondo-Wood and Haber 1994, Britten 1999). Consequently, a common critique of interview studies is that findings are not generalisable because there are too few subjects (Kvale 1996). This is, however, generally not the purpose of qualitative research (LoBiondo-Wood and Haber 1994).

Morse and Field (1996) suggest that appropriateness and adequacy are two key principles that should guide qualitative sampling. That is, participants should be able to inform the purpose of the study, as determined by the research question and stage of the research, and should provide enough data to develop a full and rich description of the phenomenon (Morse 1991). If these principles are not met then the trustworthiness of the study is threatened (Morse and Field 1996).

In this study, the sample population comprised of families attending a regional renal transplant centre in South-West England. This centre has been performing renal transplant for several decades and, according to data from UK Transplant
(2006g), between 2003 and 2005, the centre had approximately 1.97 million people in their catchment area (at the time of data collection, this area incorporated the counties of Gloucestershire, Wiltshire, Dorset, Somerset, Devon and Cornwall) and, at the time of writing, had 230 patients on their renal transplant waiting list. During this time period the centre performed, on average, 32 live transplants per annum and reported a 1 year graft survival rate, for live transplants, of 96% (3% above the national average) (UK Transplant 2006g). At the time of data collection the centre’s medical care was provided by a team comprising of one consultant live transplant surgeon, six consultant renal physicians (including one professor of nephrology), one part time live transplant co-ordinator and two clinical psychologists (although routine pre-transplant psychological assessments were not performed).

This centre was chosen because it had an outstanding national reputation for renal transplants, it was a reasonable distance from my academic base, which made travelling to it and meeting families relatively easy, and all of the staff were extremely supportive and interested in my study. At the time of my study, there was also ongoing psychological research, involving live kidney donors, in the Welsh regional renal transplant centre, which therefore precluded my study being conducted there because I would, potentially, have had to use the same small group of participants.

In this study, all the participants were specifically selected to provide descriptions of their experiences that addressed the formulated research questions and other pertinent issues identified in the literature review. Families were only
invited to participate in the study if they were waiting for a live kidney transplant (donating or receiving), already had (as far as possible), in the case of prospective donors, established that they were medically fit to donate (i.e., completed all pre-transplant assessments, including the pre-transplant angiography) and were over the age of sixteen years.

Whilst the purpose of the study was to explore the experiences of donors, recipients and their significant others, given the limited number of families involved in live kidney transplants and the time constraints associated with a PhD, I did not specifically seek 'perfect nuclear families' (e.g., comprising of a live donor and partner and a recipient and partner) to take part in the study. However, a minimum requirement for families to be included in the study was that they must at least consist of a donor and a recipient; e.g., spousal donation, which is now increasingly common in most UK transplant centres.

Families were not invited to participate in the study if any participants were under the age of sixteen years (because of ethical issues relating to matters such as consent and due to my lack of experience at that time in working with adolescents), had learning difficulties or other similar problems, such as mental illnesses (again because of the ethical issues involved) or were non-English speakers (due to costs involved in interpreting and disseminating results).

I originally estimated that approximately 6 – 10 families would probably participate in the study. This estimated number was based on several pertinent factors. For example, the number of suitable families who would be able to
participate in the study would largely depend on the number of live transplants performed during the period of data collection. In this particular transplant centre, for example, the average number of live transplants performed, at that time, was 32 per annum; approximately 1 every 2-3 weeks. Other important factors included the willingness and suitability of all potential families. Finally, it was believed that 6-10 families would be a suitable number to provide a satisfactory account of clients' experiences and would allow for a proper follow up period of data collection within the time constraints of a PhD study.

Therefore, based on these factors, if 6-10 willing, suitable families were successfully recruited in the first 6-7 month period of data collection, this would allow time for sufficient, manageable follow up interviews of all families involved in the study, in the total 18 month period of data collection.

Throughout the study, I worked closely with the live transplant co-ordinator at the transplant centre and we met or phoned each other on a regular basis to discuss the study and the recruitment of potential families. All potential, suitable families were first identified by the transplant co-ordinator and sent a covering letter and a patient information sheet outlining the study details, basic ethical principles (such as anonymity and confidentiality) and optional nature of the research (see appendix 3). These families were then invited to phone the transplant co-ordinator if they were interested in participating in the study and agreeable to being contacted by me as the researcher.
The transplant co-ordinator then notified me about all families who were willing to participate in the study and provided me with the relevant contact details. I then telephoned the families to establish if they were still willing to participate in the study, if they had any questions or concerns about the research, to ensure that they understood how the study would be conducted and to set up a mutually convenient time and place to meet.

Families were recruited into the study between July 2003 and February 2004. During this period, 20 live kidney transplants were performed in the transplant centre and 11 of these families (55%) consented to participate in the study. In total, 22 participants were recruited into the study; 11 donors (6 females, 5 males) and 11 respective recipients (6 males, 5 females). Ten donors were employed at time of recruitment (4 professional, 1 professional/managerial and 5 skilled manual workers) and one was retired. Seven recipients were also employed (1 professional, 2 semi-professional and 4 skilled manual workers) and four were unemployed due to ill health. Recipients had been aware of their renal condition from between eight months and almost three decades and had been actually waiting for a renal transplant for varying periods, ranging from several months to several years (up to 3 years), although this had no bearing on participants’ experiences.

Donors’ mean age was 50 years (age range 36 – 62 years) and recipients’ was 46 years (age range 32-63 years). Demographic details are provided in Table 2:
Table 2.

## Participant Information

<table>
<thead>
<tr>
<th>Family</th>
<th>Donor</th>
<th>Recipient</th>
<th>Date of transplant</th>
<th>Transplant Outcome</th>
<th>1st interview</th>
<th>2nd interview</th>
<th>Final interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Husband</td>
<td>Wife</td>
<td>07/07/2003</td>
<td>Successful</td>
<td>04/07/2003</td>
<td>14/10/2003</td>
<td>18/05/2004</td>
</tr>
<tr>
<td>2</td>
<td>Husband</td>
<td>Wife</td>
<td>21/07/2003</td>
<td>Successful</td>
<td>15/07/2003</td>
<td>15/10/2003</td>
<td>24/05/2004</td>
</tr>
<tr>
<td>5</td>
<td>Wife</td>
<td>Husband</td>
<td>13/10/2003</td>
<td>Cancelled*</td>
<td>25/09/2003</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>8</td>
<td>Mother</td>
<td>Daughter</td>
<td>15/12/2003</td>
<td>Successful</td>
<td>10/12/2003</td>
<td>12/03/2004</td>
<td>18/10/2004</td>
</tr>
<tr>
<td>10</td>
<td>Wife</td>
<td>Husband</td>
<td>09/02/2004</td>
<td>Cancelled**</td>
<td>27/01/2004</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>11</td>
<td>Father</td>
<td>Son</td>
<td>19/04/2004</td>
<td>Successful</td>
<td>12/04/2004</td>
<td>15/07/2004</td>
<td>16/02/2005</td>
</tr>
</tbody>
</table>

As Table 2 demonstrates, there were eight spousal donations, one brother to sister (family 4), one mother to daughter (family 8) and one father to son (family 11). Consequently, in eight of the families interviewed there were no ‘significant others’, as the donors and recipients were married to each other. Furthermore, at the time of recruitment, the donor in family 4 was single, as were the donor and recipient in family 8 and the recipient in family 11. This, therefore, only left two potential ‘significant others’ to interview; the husband of the recipient in family 4 and the wife of the donor in family 11.

However, due to work commitments at the time of the first interview, I was unable to interview the wife of the donor in family 11 before transplantation and was left with no alternative but to exclude her from the study. As a result, this only left one ‘significant other’ in the study (the husband of R4).

I discussed this matter at length with my PhD supervisors and we all felt that, whilst the views and experiences of this person would be of interest, I would not
really be able to make any realistic conclusions based on the experiences of just one significant other family member. We therefore agreed that it would be prudent to just concentrate on the experiences of donors and recipients, as there were not enough ‘significant others’ to interview. Consequently, I wrote and spoke to family 4 to explain my position to them. I also informed the LREC committee of the change in my study design (see appendix 2a/b).

It is perhaps wise, therefore, at this point, to amend and restate the research questions accordingly:

➢ What are the experiences of donors and recipients throughout the live transplantation process?

➢ Is the anthropological theory of ‘gift exchange’ a relevant framework to explore and understand the live kidney transplantation process?

➢ How may a theoretically informed, in-depth insight into these experiences be used to inform and develop future research and clinical practice?

Table 2 also shows that the transplants in family 5 and 10 were cancelled. This was due to medical problems in the donors that only emerged in the final check up, before admission to hospital. Donor 5 was found to have an elevated blood glucose level quite late in the pre-donation work up period, although her previous blood sugars had been normal. As there was also a history of type 2 diabetes in her family, her transplant was subsequently postponed indefinitely, pending further investigations. Donor 10 was found to be hypertensive quite late in her pre-donation work up, although her previous blood pressure readings had also been normal. Her transplant was also subsequently postponed indefinitely, pending further investigations.
As the post transplant interviews focused on the transplantation experience and life post transplant, I was advised by my supervisors to exclude both families from any further interviews, although data from their pre-transplant interviews were included in the study findings. I subsequently wrote and spoke to both families about my decision.

4.16 Setting and context

Unlike quantitative research, where a degree of control is often exerted over the study setting, qualitative interviews are normally conducted in more natural settings (Polit and Hungler 1993, LoBiondo-Wood and Haber 1994, Pope and Mays 1999). In keeping with this tradition, all families in this qualitative study were interviewed, by mutual consent, in their own homes, or, on several occasions at the transplant centre, at times that were convenient for them – usually around late morning to early evening. All interviews were conducted separately, in private, and with no interruptions.

I dressed casually for all interviews and did not meet any of the participants before the interviews, although, of course, I did speak with each family over the telephone, on at least one occasion, to arrange the interviews. Furthermore, as I was not employed by the transplant centre, I was not involved in any way with the medical or social care of any participants.

Whilst all interviews were recorded on audio-tape, these do, as Kvale (1996) points out, give a somewhat decontextualised version of the interview, in that they are not capable of incorporating the visual aspects of the situation. For
example, the setting and other important non-verbal cues of the participants, such as smiling, frowning and crying; all of which are important ways of communicating in everyday life. As this type of contextual data can help to provide greater meaning and understanding to the information obtained (Wengraf 2001), I compiled ‘field notes’ during each interview to record non-verbal cues such as smiling or crying. I also recorded key issues and thoughts and ideas about the interviews in the field notes immediately after the interviews were conducted and I had left the participants’ house. The purpose of this was to aid transcription and data analysis, which was always commenced on the same day as the interviews. This approach can also help to reduce the obvious limitations of the reliance on memory for interview analysis, such as the rapid forgetting of details and the influence of selective memory (Kvale 1996).

4.17 Nurse-researcher role

When conducting qualitative research, it is worthwhile considering how participants perceive the researcher and the effects that this may have on the interview. This issue is particularly important if the interviewee knows that the interviewer is also a doctor or a nurse and is especially so if the participant is also a patient of that health professional, since they may feel compelled to give ‘socially desirable answers’ that they think the researcher wants to hear (Britten 1999).

The other associated problems of interviewing one’s own patients for research purposes is that there is a potential for a conflict of interest, interviewer bias and inequalities in power relationships between interviewer and interviewee (Britten
The honesty of participants may also be questionable over important issues such as their opinions about clinical services, particularly if they are negative ones and if they think that their responses may affect their care and support or that of a loved one.

Healthcare researchers who interview patients, particularly their own patients, must create an environment where participants know they can give honest answers without fear of recrimination or correction if they say things that clinicians think are wrong (e.g., that antibiotics are a suitable treatment for viral infections) (Britten 1999).

From this respect, I felt that as I was not employed by the transplant centre, it was probably of some benefit to the study because, although I concede the contentiousness of this matter, participants were perhaps more truthful about issues such as service provision because they knew that I was not employed by the hospital that they or their loved ones were attending.

The patient information sheet explained that I was a researcher at the University of Wales College of Medicine (now Cardiff University) (see appendix 3) and before interviews took place, I also explained to the participants that I was not employed by the transplant centre. Whilst I did not routinely tell participants that I was a nurse I did, whenever asked, readily and truthfully discuss my professional and academic background with them.
Many researchers rarely acknowledge their own personal interest in their studies, perhaps through fear that such admissions will demonstrate an element of bias. However, nursing research topics, particularly doctoral nursing studies are often chosen not only for their theoretical importance, originality or significance to the discipline, but also because the researcher is interested in and stimulated by the phenomena being investigated (Lowes and Prowse 2001).

I have already acknowledged my beliefs and perspectives about the study phenomenon and indicated my support for Heideggerian philosophy, which proposes that researchers participate with participants in making data. I do, therefore, believe that a personal interest in a research area can actually strengthen the study, providing, of course, that researchers do not intentionally lead participants down a path of their own personal interest.

During an interview, it is therefore important to avoid the use of ‘leading’ or ‘loaded’ questions, which can inadvertently shape the content of an answer (Kvale 1996). This can help ensure that the experiences expressed by the participants are those of the interviewees and do not reflect those of the interviewer or the interviewer’s agenda. It should also be noted that, not only may the questions preceding an answer be leading, but the interviewer’s own verbal and bodily responses following an answer can act as positive or negative reinforcers for the answer given and thereby influence the subject’s answer to further questions (Kvale 1996). During all interviews, I endeavoured to take a non-judgemental, neutral stance. Whilst I nodded, smiled and used prompts such as the strategic use of silence or ‘mmm’ to encourage responses or to elicit
further information from participants, I never frowned or gasped at certain responses that, for example, surprised or shocked me.

The other important issue that arises when exploring the dual role of nurse and researcher is that, whilst both utilise similar interpersonal skills, the actual roles are fundamentally different. That is, the research interview is somewhat different to a helping or therapeutic interview that may be used in the course of nursing practice or counselling:

'The main purpose of the research interview is to listen attentively to what the participant has to say in order to acquire knowledge and develop greater understanding. It is not to offer any form of therapeutic help, advice or counselling (although many participants may find the opportunity to talk about their experiences cathartic or quasi-therapeutic), which many interviewers have neither the training nor the time for' (Kvale 1996, p.155).

However, some participants, particularly if emotionally unstable, may attempt to turn a research interview into personal therapy (Kvale 1996). But as this is not the purpose of the research interview, it should be avoided at all costs by ensuring that the interviews do not intentionally promote a therapeutic relationship and that procedures are in place for dealing with such situations (e.g. simple explanations) if and when they arise.

Nevertheless, some interviews may involve strongly personal and emotional issues that may, in some cases, bring forth deeper personal problems requiring therapeutic assistance (Kvale 1996). If and when such situations do arise it is wise to ensure that appropriate mechanisms are in place, such as 'backup' therapists, counsellors or help groups, for dealing with personal problems that are brought up by the interview.
For the benefit of myself, and especially that of participants, I originally foresaw that such issues might arise during the course of the study. I had planned to address these issues, if and when they ever arose, through regular meetings with my academic supervisors and also through regular clinical supervision sessions with a clinical psychologist who was based in the transplant centre at the hospital of study and who also offered professional support or help to participants, if required. To protect participants' identities, both academic and clinical supervision sessions were anonymised.

On one occasion, a participant, a female recipient, asked me specific questions relating to her illness during and particularly after her pre-transplant interview was over. However, I, just like her medical team as it transpired, did not know the answer, as it was very specific and unusual. I did tell her that I was unsure and during the interview explored, through careful questioning, if she was aware of how to go about probing her health team further for answers to questions that were clearly bothering her. She confirmed to me that she knew how to go about this but she was quite reticent as to why she had failed to do so.

As a novice interviewer, I was also aware of the need to ensure that my interview schedule and interviewing skills were sound. I therefore decided to undertake a pilot interview with the first family recruited into the study to explore the understandability of the formulated interview questions and to review my interviewing skills. This and all interview transcripts were therefore shared with
my primary PhD supervisor to critically explore these issues and consider how I could develop into a more competent research interviewer.

This family also served as the 'pilot family' for all interview schedules throughout the study. However, none of the interview schedules had to be changed in any way and therefore the data from these interviews have been incorporated into the main study findings. I also felt that, during the course of the study, my interviewing skills improved significantly, through critical reflection and appraisal. Furthermore, despite being asked to discuss their experiences, I found that very few participants talked spontaneously about service provision issues. Therefore, if they did not raise this matter during the course of the interview I directly asked them, ‘How have you found the transplant service throughout this process’? Responses were then followed up accordingly. The interview schedule can be found in appendix 5.

4.18 Ethical considerations

4.18.1 Ethical approval

Full ethical approval for this study was applied for in April 2003 and was subsequently granted on 21st May 2003 by the appropriate local research ethics committee (LREC) (see appendix 2).

4.18.2 Informed consent

All participants identified as being suitable for inclusion into the study were initially sent an LREC approved patient information leaflet (see appendix 3) by the live transplant co-ordinator. As discussed earlier, this leaflet provided
potential participants with sufficient, understandable information (in lay terms) about the study, such as the purpose of the research, how it would be conducted and how it was separate from their medical care and treatment. It also assured the reader of the fundamental ethical principles of anonymity, confidentiality (except in certain exceptional circumstances – e.g., if the participant expresses a desire to hurt another person) and the right to withdraw from an interview or the study at any time without prejudice and without it affecting their care.

I then telephoned all families who volunteered, through the transplant co-ordinator, to take part in the study to establish if they had received, read and understood the information sheet and if they had any queries or concerns about the study. If, at this stage, they were still happy to participate in the study, a meeting was then arranged (none withdrew at this stage).

At the first pre-transplant interview meeting, I once again provided all families with further verbal information about the study, such as how and why it was being conducted, their basic rights of confidentiality, anonymity and right to withdraw and, again, asked them if they had any questions or queries regarding the study. At this stage (as highlighted in the original patient information leaflet) families who agreed to take part in the study were asked to sign a consent form which demonstrated that they were happy, informed and willing to take part (see appendix 4).

All families were also contacted, by telephone, prior to the follow up interviews, at 3 and 10 months post transplant, to establish if they were still happy to proceed
with the study and to arrange suitable times and dates to conduct further interviews. No families withdrew from the study at this stage.

4.18.3 Confidentiality

To ensure the anonymity and confidentiality of all participants’ data, such as audiotapes, were coded (e.g., family 1, family 2 etc.) and stored in a locked cabinet at home. These tapes will be retained in accordance with Cardiff University directives.

Information regarding participants was stored on a secure, personal PC (used only by me), using pseudonyms, which can only be accessed with a password. Furthermore, names of participants and health professionals have not been used at any stage of this study, nor will they be in any future publications, that could identify them. For example, in the findings section of this thesis, names, hospital and place names have been removed.

No personal information about participants was relayed to staff at the transplant centre or my academic supervisors and, therefore, all references to study participants at academic and clinical supervision sessions were anonymised to protect participants’ identities.

4.19 Rigour

Rigour, or trustworthiness, is an essential element of any research endeavour that helps to ensure that research findings are credible and valid (Cutcliffe 1997, Holloway and Wheeler 2002, Mill and Ogilvie 2003). Failure to establish and
maintain methodological rigour can result in weak, ambiguous or meaningless research findings and may even result in wasted research time and effort (Long and Johnson 2000).

The concept of rigour, however, is highly contentious in qualitative research and considerable discordance exists amongst qualitative researchers about how, and even whether, rigour can be achieved in qualitative studies. Methodological rigour is commonly established and assessed through the concepts of reliability and validity. But while these terms have distinct meanings, which relate well to other concepts and assumptions within the logical-positivists paradigm, their use in qualitative work has been questioned (Long and Johnson 2000, Mill and Ogilvie 2003). Holloway and Wheeler (2002) add:

>'Many writers suggest that the concept of rigour has no real place in qualitative research because of its particular connotations with measurement and objectivity' (p. 251).

Unfortunately, there is no consensus on how to tackle the problem of reliability and validity in qualitative research. Instead three distinct perspectives exist that argue that:

- Qualitative and quantitative research should be evaluated by the same criteria
- As qualitative research represents an alternative paradigm of knowledge acquisition to quantitative research, the criteria used cannot simply mimic those to test quantitative studies. Qualitative research should, therefore, be evaluated by specifically developed criteria
- The character of qualitative research means that it is simply not possible to apply criteria to judge it and, therefore, criteriology should be rejected (Hammersly 1992, Carter and Porter 2000, Holloway and Wheeler 2002).

Many authors have argued that instead of borrowing concepts and terminology developed and used within the quantitative-positivistic paradigm, a
reconceptualisation of the criteria and terms that are used to assess the quality of qualitative research is required. Guba and Lincoln (1989) and Sandelowski (1993) have been at the forefront of this movement and have suggested the following alternative notions:

- Rigour – Trustworthiness (why research findings should be believed)
- Reliability – Dependability (findings should be consistent and accurate)
- Validity – Credibility (findings should be compatible with the perceptions of the people under study)
- Generalisability (external validity) – Transferability/Fittingness (is it possible to transfer findings in one context to similar situations or participants)
- Objectivity – Confirmability (findings should achieve their aim naturally, not because of the researcher’s prior assumptions and preconceptions)


Beck (1994b) maintains that this reconceptualisation reflects a different kind of discourse and carries with it a different sense of the research process. However, Long and Johnson (2000) argue that many of these alternative terms have the same essential meaning, and nothing can really be gained from clouding the issue with alternative labels for what are arguably identical concepts. Whilst I do not entirely agree with this position, I do feel that some of the above concepts, notably generalisability and transferability, have very similar meanings.

Although researchers have not agreed upon one particular set of criteria, many would probably concede that rigour in qualitative research must be ensured or its value, worth and credibility will be seriously questioned. Burnard (2000) rightly states that:

‘If qualitative research is to do more than simply report individuals’ accounts of their experience and if it is to attempt to draw together those accounts and thus theory-build, the processes that are employed in that
work must be subject to rigour and to reliability and validity checks’ (p.36).

Greenhalgh and Taylor (1997), however, maintain that the strength of qualitative research lies in its validity (closeness to the truth) rather than its reliability (repeatability). Sandelowski (1993) believes that one of the most important threats to validity in qualitative projects is the assumption that validity rests on reliability, and argues, quite reasonably I believe, that repeatability is not an essential property of qualitative research. Because of the unique nature of qualitative inquiry, including the type of data, the sample and the philosophical and theoretical beliefs of the researcher (who is after all the main research instrument in qualitative research) the research can never be wholly replicable (Sandelowski 1993, Long and Johnson 2000, Holloway and Wheeler 2002). Other investigators will have different emphasis and foci, even when they adopt the same methods and select a similar sample and topic area (Holloway and Wheeler 2002).

Furthermore, participants participating in qualitative research discuss their beliefs, views and experiences of a phenomenon at a certain point in time. Therefore, if the same study was repeated with different subjects, or even with the same subjects but at a different point in time, it is questionable whether the study findings would be consistently the same. Even if the findings were identical, similar or completely different, the studies would be no less valid, providing they had both been conducted rigorously.
However, as with many methodological issues in the naturalistic paradigm, opinions regarding validity in qualitative research vary significantly and much debate exists about whether it is possible to develop methods that could properly address the concept of validity in all types of qualitative inquiry.

Due to the nature of qualitative research, I take the view that validity, in an objective-measurement sense (as applied in quantitative research), does not have the same fundamental meaning in qualitative research. For example, Hammersley (1992) maintains that, in qualitative research, an account is valid or true if it represents accurately those features of the phenomenon that it is intended to describe, explain or theorise.

I do, however, believe that it is important for researchers to attempt to address the issue of validity in qualitative research. Otherwise, as Silverman (1997) states:

‘If social science statements are simply accounts, with no claims to validity, why should we read them’ (p.155)?

A number of strategies are available to help establish and maintain validity within qualitative research. The most common methods are; participant validation, searching for negative cases and alternative explanations, inter-rater reliability (also called peer debriefing/peer review), triangulation and the audit or decision trail (Greenhalgh and Taylor 1997, Long and Johnson 2000, Holloway and Wheeler 2002).

But deciding on which strategy (or strategies) is the most appropriate for a particular study is no easy task since not all of these strategies are universally
accepted and no one method is seen as the panacea to addressing rigour in qualitative research. Koch (1996) advises that:

'It is my opinion that an inquirer needs to engage in this literature and select or develop the most appropriate criteria for their particular study. The responsibility lies with the writer to show the way in which a study attempts to address the issue of rigour' (p. 178).

I have therefore decided to explore these main strategies to make an informed choice as to which method(s) I feel is the most suitable for use in this study.

4.20 Participant validation

One of the validation processes commonly employed in qualitative inquiry, particularly in phenomenological research, is participant validation (also referred to as member checking). Participant validation involves returning to participants and asking them to carefully read through their interview transcripts and/or data analysis for them to validate, or refute, the researcher’s interpretation of the data (Beck 1994a, Koch 1994, Mays and Pope 1995, Caelli 2001, Maggs-Rapport 2001).

This procedure is said to offer many benefits to the research process such as empowering participants, by giving them some control of the research itself, and it also provides participants with the opportunity to change mistakes that they feel they may have made during the interview (Holloway and Wheeler 2002). If discourse between participant and researcher is particularly constructive, it may also help to extend the ideas and thinking of the researcher and may, therefore, help in the refinement of theme and theory development. However, the primary purpose for undertaking participant validation is to help avoid misinterpretation
or misunderstanding of the participants' words or actions by clarifying meanings and emerging themes with the participants themselves (Holloway and Wheeler 2002). Thus the process is supposed to help ensure that findings are based on what the participants really think and feel and not on what researchers, possibly influenced by their background perspective and beliefs, believe they think or feel.

There are, however, several fundamental problems associated with participant validation. Firstly, it requires a significant time commitment from both the researcher and the participants. Secondly, some participants may become defensive, anxious and may even deny ideas disclosed during interview, which they now feel are 'less desirable' (Long and Johnson 2000, Holloway and Wheeler 2002). Also, if participant validation does not take place relatively soon after data collection and analysis, then the participants may have changed their perceptions and views because of the temporal effects and because of potential changes in their situation, health and, perhaps even, as a result of participation in the study (Long and Johnson 2000, Holloway and Wheeler 2002). The major problem with this, of course, is that if participants want to later amend their accounts, because they now feel differently, the modified data will not accurately reflect how they actually felt at the time of the original interview. Thirdly, some participants may find the process exploitative and distressing (Barbour 2001), particularly if they have to relive an experience that was emotionally demanding at the time of the original interview. Researchers also need to carefully consider how to present the information, such as transcripts and analyses, to people who are likely to be non-academics.
It has also been suggested that if a close relationship has developed between researcher and participant (which seems quite likely in longitudinal studies, where there is repeated contact between researcher and participant – my emphasis) it may prevent participants from adopting a critical stance (Holloway and Wheeler 2002). Alternatively, some researchers may choose to disregard their own interpretations and to accept those of participants at face value (Barbour 2001). Whilst this may be ‘cosy’, it may actually lead to collusion and simply result in the uncritical ‘romanticising’ of participants’ accounts (Barbour 2001).

However, there is also the possibility that there will be no agreement between the parties involved, in which case the researcher has to consider how best to deal with a potential insuperable impasse. All of these realistic scenarios undoubtedly raise the question of precisely how much faith can be placed in the results of participant validation. Hammersley and Atkinson (1995) state that:

‘We cannot assume that anyone is a privileged commentator on his or her own actions, in the sense that the truth of their account is guaranteed’ (p. 229).

Finally, and perhaps most significantly, one of the major problems associated with participant validation is that whilst participants may, or may not, be able to elucidate the researcher’s interpretation of their previous individual commentaries, they will not really be able to validate emerging themes and theories that have been formulated from collective discourse. As Cutcliffe and McKenna (1999) explain:
'It is somewhat unlikely that each interviewee will recognise and thus verify the representativeness of the entirety of the emerging theory as each of them will have contributed only a portion of the data. Therefore it is quite possible that some participants will not recognise some of the emerging theories' (p.378).

Because of these issues, I feel that participant validation would be unhelpful in my study and I have therefore decided to reject this procedure as a validation tool.

4.21 Triangulation

Triangulation is now used increasingly as a validation procedure in research studies, which perhaps testifies both to the respect accorded to this concept and to its perceived value in demonstrating rigour (Barbour 2001). Although there are several types of triangulation, the most common form, by far, is methodological triangulation. This process involves collecting data in several different ways, such as from participant observations, interviews, focus groups and questionnaires, in order to answer a research question (Greenhalgh and Taylor 1997, Barbour 2001). Obtaining and corroborating data from several different sources is believed to provide a broader overview of the topic area and to reduce the disadvantages inherent in the use of any single source or method (Keen and Packwood 1995, Cutcliffe and McKenna 1999, Long and Johnson 2000).

However, triangulation does not automatically demonstrate validity and is often difficult to perform properly, in that data collected using different methods come in different forms and consequently defies direct comparison (Holloway and Wheeler 2002, Barbour 2001). Also, even if data obtained from different sources corroborate, it doesn’t necessarily mean that they are all correct. As Cutcliffe and McKenna (1999) point out, if multiple sources of data provide inaccurate results,
then all this method will do is confirm and support an inaccurate theory.

However, if the most appropriate research methods are used, then there seems less likelihood of this occurring.

Perhaps the most noteworthy comment on triangulation comes from Bloor (1997), who states that:

'If it is accepted that for any given topic there will be one best method of data collection then triangulation may be said to involve juxtaposing findings gathered by the best available method with findings generated by an inferior method' (p.38).

I have decided not to use triangulation as a method of validation. This is, in part, because of some of the issues discussed above but also because I feel that my sample group is of a size that would be insufficient to encompass any quantitative method to achieve triangulation. Also, given the nature of my study, I feel that it would be impractical and perhaps even impossible, to utilise certain qualitative research methods, such as participant observation, in participants’ homes and/or when they are recovering from a surgical procedure in hospital.

4.22 Inter-rater reliability

Inter-rater reliability (also referred to as peer review or peer debriefing) is another validation procedure that is used with increasing frequency in qualitative research. This process involves at least one other suitably experienced researcher independently reviewing and exploring interview transcripts, data analysis and emerging themes. It has been argued that the involvement of an additional experienced qualitative researcher may help to guard against the potential for
lone researcher bias and help to provide additional insights into theme and theory development (Andrews et al 1996, Cutcliffe and McKenna 1999, Barbour 2001).

However, as with other qualitative validation techniques, inter-rater reliability is not without its problems. For example, what constitutes an ‘experienced or expert reviewer’, on what basis should they be selected and how productive and beneficial is such a collaboration likely to be if there has been no similar collaborations in the past and/or the researchers’ clinical, academic and philosophical background and beliefs differ (Cutcliffe and McKenna 1999)? It has also been suggested that inter-rater reliability smacks of naive realism, since it is quite likely that each researcher will interpret the data (or parts of it – my emphasis) differently (Seale 2000). Also, if both perspectives are grounded in and supported by the data, is one interpretation necessarily stronger or more valid than the other?

However, I would also argue that some qualitative researchers believe that if concordance can be reached by two separate researchers, then any subsequent findings and conclusions will somehow be more credible and trustworthy.

Cutcliffe and McKenna (1999) state that:

'Enlisting the help of others to verify categories and themes somehow suggests that if more than one person thinks or agrees with categorisation then this must be more accurate than one person's categorisation. If this argument is expanded, it begins to support the positivistic philosophy that there is only one accurate interpretation, only one reality and that the accuracy of an interpretation is increased as the number of people agreeing increases' (p.377).

Probably, though, the greatest problem with this process, and the primary reason for me rejecting it as a validation technique, is that in studies influenced by
Heideggerian phenomenology, data are co-created by researcher and participant. Furthermore, researchers like myself, subscribing to this approach, recognise and identify their pre-understandings throughout the research process and utilize these in the interpretation of data. Therefore, it is arguably improbable for another researcher not directly involved in the study, however experienced they may be, to analyse and interpret the data in the same meaningful way.

However, although I did not use inter-rater reliability as a validation technique, for the reasons described above, I did share all transcripts with my primary PhD supervisor, to discuss emerging themes, theories and categories. These were also regularly discussed with my second supervisor and clinical supervisor. The purpose of these sessions, however, was not to seek concordance of opinions regarding thematic generation, but to constructively extend my interpretation of the data and emerging themes. I found this process extremely helpful and was a valuable aspect of the supervisory process.

4.23 Searching for negative, or alternative explanations

Manipulating data (like literature) to make them show what you want them to show is a relatively easy task, but any subsequent findings and conclusions are likely to be incomplete, inaccurate and possibly untrue. However, the validity of studies can be enhanced if researchers search for and identify data (if, of course any exists) that do not easily fit into the developing theory or their own ideas (Holloway and Wheeler 2002). Such thoroughness can help to demonstrate that the entire dataset has been considered and not just a subsection that, perhaps, suits the developing themes. Where, of course, there are anomalies or variations
in the data, every effort should be made to satisfactorily account for these (Mays and Pope 1995, Polit and Beck 2005).

This is also a fundamental element of the ‘hermeneutic circle’, where researchers using this approach, constantly search for new or alternative meanings in the text. I think that this procedure is essential to any research endeavour and I have therefore decided to use it as one of my validation strategies.

4.24 The audit or decision trail

The audit, or decision trail, involves clearly describing methodological and philosophical decisions, such as data collection and analysis procedures and providing sufficient information about contextual data (e.g., the physical environment and organisational issues) and researcher beliefs and assumptions (Beck 1993, Koch 1994, Atkinson 1995, Koch 1996). This process allows other readers to follow the decision trail used by the investigator in the study and can therefore help to clarify the research process, establish transparency and hence demonstrate trustworthiness (Sandelowski 1986, Koch 1994, Andrews et al 1996, Koch 1996). Whilst readers may not necessarily share the author’s decisions and interpretations, they should at least be able to follow the way in which the author came to them (Koch 1994).

However, the undeniable drawback with this validation process, as Burnard (2000) points out, is that there is a danger that, in theory, virtually any research practice will be acceptable as long as you clearly describe what you have done. Consequently, I don’t believe that an audit trail necessarily provides an absolute
guarantee of methodological rigour. Nonetheless, I do feel that an audit trail can help to demonstrate that all research decisions have been carefully considered and justified and that, where appropriate, alternative approaches have been properly contemplated and rejected. This conscientious approach can, therefore, help to establish methodological rigour and will also allow other readers to make an informed judgment on rigour. I believe that an audit trail is essential to any research project, whether qualitative or quantitative, and I have therefore decided to utilise this process in this study.

Rodgers and Cowles (1993) suggest that there are four types of audit documentation that can contribute to rigorous research; contextual, methodological, analytical and personal response. The contextual documents should contain excerpts from field notes of observations and interviewing, the description of the setting, people and location (Holloway and Wheeler 2002). Methodological documents include methodological decisions made throughout the research project and the rationale for these decisions. Analytical documents consist of detailed notes of all phases of data analysis, including reflections on the analysis of data and the theoretical insights gained (Rodgers and Cowles, 1993). Personal response documents describe the thought processes and demonstrate the self-awareness (including preconceptions and background beliefs) of the researcher (Holloway and Wheeler 2002).

To address these issues, I completed field notes, which documented issues such as contextual data, participant behaviour before, during and after the interview and my own personal thoughts and feelings, as soon as practically possible after
each interview. I usually attended to these in the car immediately after leaving
the interview and/or on returning home that day to transcribe the interview.

These documents were saved in handwritten and hard copy form and kept with
the interview transcripts to add further meaning to interview data. I also kept a
personal interview diary in which I reflected upon each interview session. This
was also completed as soon as practically possible, usually the same day as the
interview itself. This file included how I felt about the interview, what I had
learnt from it and how I felt my interviewing skills were developing. I believe
that this process will help to form a decision trail that other readers can follow.

4.25 Data analysis

All interviews were audio-taped using a micro-cassette recorder and personally
transcribed verbatim as soon as possible, usually starting on the same day as the
actual interview(s). I did this to familiarise myself with the data as quickly as
possible while the interviews were still fresh in my mind.

As previously stated, I also compiled ‘field notes’ during and immediately after
each interview, detailing contextual information (e.g., the interview setting),
observations made during the interview (e.g., participants crying or laughing)
and initial thoughts and ideas relating to the data. During transcription I then
incorporated this information into the interview transcripts to make greater sense
of each interview.

I analysed the data using a form of thematic content analysis recommended by
Burnard (1991). Whilst transcribing, I carefully listened to each interview and
inserted in my own thoughts, ideas and interpretation of the data. When this process was complete, I then read and re-read each interview transcript to identify and develop themes, categories and theories that were clearly emerging from the data (see appendix 6).

A working list of coding categories was then drawn up by continually repeating this process up to and until all interview transcripts were collated. Transcripts were then re-read alongside the list of categories to establish the degree to which the categories covered all aspects of the interviews (Burnard 1991) (see appendix 6). This process can help to ensure that premature inferential leaps are not made and also allows for refinement and adjustment of coding categories (Burnard 1991, Mays and Pope 1995, Pope et al 1999).

Each coded section of the interview transcripts were then cut out and all items of each code collected together. The cut out sections were then pasted onto sheets in the appropriate category and filed together for direct reference when writing up the findings (Burnard 1991). Furthermore, as discussed earlier, all transcripts were shared with my primary PhD supervisor, not to seek agreement, but to extend my thinking about theme and theory development.

Whilst I did consider using a Computer Assisted Qualitative Data Analysis Software (CAQDAS) package, such as NUDIST or ATLAS, to assist in data analysis, I did not actually use any such programmes. There are, of course, pros and cons of using computer software to analyse qualitative data. Such packages are ultimately tools for managing large amounts of data. Computer packages do
not, though, confirm or deny the scientific value or quality of qualitative research, as computer aided analysis is merely an instrument and as good or as bad as the thinking and judgement of the researcher who uses it (Holloway and Wheeler 2002). However, CAQDAS can help demonstrate that findings and conclusions from studies are based on rigorous analysis by examining the whole corpus of data to ensure that recurring patterns, pertinent issues and negative instances have all been searched for (Seale 2000).

I enrolled on a CAQDAS trainings session after I had completed data analysis and written up most of my findings. Therefore, even though I retrospectively entered data into ATLAS, the actual analysis process and management of data was complete and the use of this software did not, therefore, contribute anything further to the study.

4.26 Conclusion

This chapter has identified the formulated research questions and discussed the research methods used to conduct the study. In the subsequent three chapters, data from the three phases of interviewing are presented.
CHAPTER FIVE: The interviews: Pre-transplant

5.1 Introduction

In this chapter, data from the pre-transplant interviews are presented. I have attempted to present the data as told by the participants themselves, as free as possible from any interpretation. However to provide some structure, coherence and clarity to these accounts I have organised participants’ experiences into themes and categories that emerged from the data during the transcription and analysis process. I therefore acknowledge that a certain level of interpretation has occurred but, for the purposes outlined above, I feel that this is unavoidable.

All interviews were conducted in private with each participant. Most pre-transplant interviews were conducted in the participants’ homes, although two families were interviewed, at their request and for their convenience, in a private room in the out patient’s department at the regional transplant centre.

To maintain anonymity and confidentiality, participants are identified by a letter, which indicates whether they are a donor (D) or a recipient (R), and a number, which indicates the order in which the family were originally recruited into the study (1-11). For example, Family 1 would be D1 (donor 1) and R1 (recipient 1), family 2 would be D2 (donor 2) and R2 (recipient 2) and so on. The relationship between the donor and recipient is also indicated. For example, D1, husband (donor 1, husband of the recipient) and R4, sister (recipient 4, sister of the donor). Names of health professionals and hospitals have also been removed to protect anonymity and confidentiality.
In total, 11 families were interviewed pre-transplantation. Experiences recounted by the families are, at times, common to all or most participants. However, certain other experiences are only reported by some participants or were unique to one or two participants. To avoid implying that certain experiences are universal, or constantly referring to the actual number of participants who have discussed a certain phenomena, I have indicated in the text, where appropriate, if experiences are common to all, most (the majority), some (several) or are simply unique to just one or two. I have also discussed, where appropriate, disparate participant experiences. Where appropriate, verbatim quotes have been used to illustrate emergent themes and issues. Throughout the study, I have attempted to incorporate the views of as many of the participants as possible. However, due to word limits, extracts have often been chosen that concisely convey the issues raised.

Experiences discussed by families in the pre-transplant interviews progressed through several distinct phases, including:

- Discovery of condition and acceptance of the need for transplantation
- Effects of the illness on life and lifestyle
- Treatment issues and options
- Coping strategies
- The decision making process
- Feelings and concerns about the impending transplant
- Donor-recipient relationships
- Transplant service issues

5.2 Discovery of condition and acceptance of the need for transplantation

Most participants, particularly recipients, began the interview by discussing when they first discovered that they, or their loved one, had a kidney problem. Most recipients had known about their condition from between approximately 8
and 20 years, although two had only known for a year or two. Causes of renal failure in recipients were hypertension, polycystic kidney disease and was, in one instance, iatrogenic (caused by inappropriate drug administration given to treat an inflammatory bowel condition).

Some recipients recalled being unwell, which had prompted them to visit their general practitioner (GP), and eventually led to the diagnosis of their condition. One recipient learnt about his condition following a routine employment medical for the fire service. Another recipient discovered his condition after going to his GP with his brother to be tested for polycystic kidney disease after they discovered that their father had the condition and that they, therefore, may also be affected.

Most recipients were told by their GP or a hospital consultant that they had a chronic kidney problem. All participants experienced a grief like reaction, accompanied by an initial feeling of shock, when they heard the diagnosis:

"It was a bit of a brutal thing really...I was sat there completely shell shocked when they told me I'd got it.... She was completely unaware of the fact that I didn't already know. So she just blurted out things and I was sat there completely blown away by the whole thing. She said sorry I thought you knew."

(R10, husband, 1st interview).

Most donors also felt shocked on discovering that their loved one had a chronic kidney problem. R11 had visited his GP after suffering headaches and blurred vision. He was examined by his GP who immediately sent him into hospital where a diagnosis of hypertension and chronic renal failure was made the same
day. His sister returned to their parents’ house that evening and broke the news to
them, after visiting her brother in hospital:

"The daughter had come home and told us and she was all in tears. We
found out from her which ward he was in and went down there. That’s
when he told us he had kidney failure. We went what...? We were
completely shook, we just didn’t know what to do to be honest. We came
home... I was just sort of walking around thinking what the hell do I do
and how do I do things. The missus was crying her eyes out."
(D11, father, 1st interview).

Some recipients expanded further their feelings about the diagnosis, explaining
how their initial feelings of shock soon turned to denial and anger:

"I didn’t want to accept it... I was in denial I refused to believe, I found it
very difficult to accept that my kidneys were packing up. Although I was
not able to go to work and was off sick and I thought oh maybe I’ll feel
better tomorrow."
(R4, sister, 1st interview).

Recipients whose renal failure progressed slowly over a number of years
commonly spoke of getting on with their lives, particularly when they were
asymptomatic:

"I wouldn’t say I buried my head in the sand but I thought well nobody’s
going to do anything about it for quite a long time so I’ll just get on with
my life, which I did."
(R3, wife, 1st interview).

Many recipients did not realise at first how serious their condition was. Some
thought their renal failure was perhaps reversible, or treatable with a course of
medication. However, all participants, both donors and recipients, eventually
came to realise that chronic renal failure was not a reversible condition and that,
consequently, some form of dialysis and/or a kidney transplant would be required
some time in the future. This eventual recognition and acceptance of the situation
usually came either after speaking to a doctor or when recipients’ renal function declined to a level that began to affect their general health and well-being:

"And 3 years ago, I suppose, things started coming to a head and I started dealing with the simple fact that... I was going to need a transplant.... By which time it had become very matter of fact really...."

(R7, husband, 1st interview).

5.3 Effects of illness on life and lifestyle

The lives of all participants had been affected, to a varying extent and in many different ways, by the recipients’ kidney failure. The effects of the renal failure were physical, psychological and social in nature and impacted on the lives of recipients (primarily), donors (particularly spousal donors) and their immediate families.

Although the severity and extent often varied, recipients’ most common physical problems were tiredness, irritability, general aches, itching, altered sleep patterns, decreased physical activity, difficulty in concentrating and nausea and vomiting. However, by far, the most common physical complaint reported by all recipients was lethargy, which most found to be frustrating:

"So now I just get up and I feel awful, knackered, no energy, you know, and I just feel like, I can't be bothered. And I hate it because I'm somebody normally who, as soon as I get up, I go all day, until I go to bed, and that is what I'm used to doing, that is what I like doing."

(R3, wife, 1st interview).

Recipients whose physical health was most affected by their illness lived almost constantly with a severe lack of physical energy. They often had to pace themselves or take things easy just to get by on a day-to-day basis. This adjustment to their lives was not necessarily out of choice, but because they no longer had the energy they once had. This often affected their ability to do things
like work, housework and decorating and often led to them sleeping for long periods, day and night, because they didn’t have the energy to stay awake:

“And before I went on dialysis I was probably sleeping 20 hours a day. I’ve never ever experienced anything as debilitation as the kidney... And I mean I go to bed at 6 or 7 o’clock at night....”

(R4, sister, 1st interview).

Most spousal donors noticed a change in their partner’s health as a result of their illness. Some donors (mainly spousal donors) and recipients (particularly) also complained of psychological or emotional problems associated with kidney disease. The most common problems reported were depression, anxiety, feelings of uncertainty and loss of control:

“I mean it is depressing, and if I spent too long thinking about it there’d be self pity and regretting what I couldn’t do. I would become very depressed and suicidal and not seeing any point in.... It sounds ridiculous but at its worse, that is what it’s like.”

(R4, sister, 1st interview).

The recipients’ chronic renal failure also impacted on their, and their families’, social life, work and family life. Some recipients experienced such a deterioration in their physical health over the last few months or years that they could no longer keep up with the demands of work. Some had increasing periods of absence from work as their illness progressively worsened, whilst others had to give up work completely. All recipients affected in this way found this profoundly difficult:

“I was working full time in a managerial position and I had to give up work, and I’m now on disability living allowance. So it’s kind of letting go of working of the responsibility and I found that, at that time, intensely difficult. I didn’t want to give up work. I fought to stay but I wasn’t able to do my job, so that had to go.”

(R4, sister, 1st interview).
Some recipients also had to give up, or reduce the time they spent doing things they enjoyed such as hobbies, sports and DIY because their physical condition, mainly their lack of energy, no longer allowed them to do so:

"I like to think of myself as quite sporty. I'm very interested in martial arts and I've found that I can't actually do... what I actually want to do. I tire very quickly... and that's a little bit frustrating, because you know that you can do so much better, or you hope you could anyway."

(R7, husband, 1st interview).

Many recipients and donors (mainly spousal) said that the recipients' illness also affected the life of the family and, in the case of spousal donors, their life together as a couple. Many experienced a reduced social life, some were unable to go on holidays together or with their family, or enjoy hobbies or interests together. In some cases, the recipient's renal failure restricted, and occasionally strained, spousal and family relationships, particularly if the recipient was becoming increasingly dependent on others and/or had to deal with the demands of dialysis:

"We like going out and I do try and make a point of going out on a Saturday with my husband, but there's times where I'm so tired I say you go. I can't even go, because I don't feel like it, you know... that's how I am in myself.... Everything seems to be an effort and that's not like me really because I've always been a very independent person really (laugh) and done all my own things...."

(R2, wife, 1st interview).

Some recipients also spoke about the effects that their illness had on their spouses and immediate family, recognising that their condition not only affected their lives but also the lives of others, and they were troubled by this. R4 discussed how difficult things had been for her husband and their family. She felt that her husband had less of a social life because of her illness, as he had to spend more time with her due to her deteriorating health. She felt contrite about this
and said that, at times, she pretended to be better than she actually was, for his sake:

"The strain on my husband has been absolutely intense and for my sons, and for my mum and... and because as you know kidney patients can be well and then suddenly extremely unwell. And I still find it very difficult to get my head around that.... It's been very, very hard. I'm aware of how hard it is for my husband, so I want to be better and maybe pretend to feel better than I am so that he feels... because he's ok when I'm ok, but it's not easy."

(R4, sister, 1st interview).

The lives of all participants were affected to some extent by the recipients' renal failure. However, the lives of some had not been significantly affected until recently because, in these cases, the recipients had experienced very few physical problems. Even these recipients, though, found that their general health and lifestyle were adversely affected as their kidney function deteriorated the closer they came to transplant:

"I think I've had a pretty normal life really up to the past year or so I would say, when the kidneys have really started to fail. But before that I had done everything that I had wanted to do and it hasn't really stopped me doing what I wanted to do, apart from really in the last year. I think because they were failing more rapidly it's been more hospital appointments, that sort of thing, and of course I started dialysis in September and so that's been the biggest change.

I'd say with travelling, because my son and I like to go to Australia, but of course I haven't felt happy about travelling, knowing that the kidneys were really packing in. But I've carried on working and I've carried on a full social life and everything like that. Even on dialysis I've travelled around the country and gone to different places and done it all over the place. But it does restrict you slightly, but not as much as I thought it would do."

(R8, daughter, 1st interview).

R11 said that he tried not to let his life be significantly affected by his condition:

"Oh no way. There's things I can't eat, there's certain things I can't do but I think nah, bugger off. I'm still doing what I'm doing.... To me if I let the disease take control then I'll go down with it and there's no way."

(R11, son, 1st interview).
5.4 Treatment issues and options

Most recipients (and some donors) discussed the treatment issues associated with renal failure, focusing on drug, fluid and diet regimes and, in particular, dialysis. R1 spoke about her medication regime, which included having to take a variety of tablets (such as diuretics and iron supplements), which she detested, and receiving regular erythropoietin injections to maintain her haemoglobin levels. Some recipients explained how their renal failure resulted in them having to make fluid and/or dietary changes. This often involved having to eat low potassium, low phosphate or low protein diets and restricting their intake of certain types and volumes of fluids (especially if they were on dialysis). These recipients found this aspect of their illness quite difficult as it involved them having to make quite significant changes to their life, such as reducing or even giving up eating and drinking things that they enjoyed. Recipients affected in this way explained how hard these changes were for them and how difficult they found it to be disciplined:

"I've never been a huge eater and obviously when they told me about the diet, which is the thing that shocked me more than anything.... They just called me in one day and said 'right from now on you mustn't have this and you mustn't have that', and I said well that's impossible (laugh). You've got to weigh this and do that, and get your little booklet and try and be good but it is very hard, so I cut down very much.... I have a little of a lot of different things rather than being too good about it... because in my mind it was taking away a decent diet.... You're having all this stuff that's not good for you, which I found strange, but I got by.

Your food is, let's face it, a big part of life isn't it? And then things that I love like cheese... fruit juice, that is, oh my god, when I stopped drinking that, and then you're down to drinking water, when you're out, I drink water an awful lot. I don't mind, it doesn't worry me, I'm not a drinker anyway...."

(R1, wife, 1st interview).
The regional transplant centre in this study routinely performs pre-emptive renal transplants (transplants performed prior to total loss of renal function, which generally avoids the need for any form of dialysis) where appropriate and if possible. However, this treatment option is not always possible, e.g., if a suitable donor cannot be found in time or if the patient's renal function deteriorates so quickly that dialysis is unavoidable.

At the time of the first interviews, most recipients had received some form of dialysis and were, at that stage, actually on peritoneal dialysis (CAPD). However, a common view expressed by most recipients, regardless of whether or not they were actually receiving dialysis, was that it was not a form of treatment that they wanted. Various reasons were given for this, including fear and concern about dialysis, particularly the demands of a dialysis regime and the potential effects it would have on their life and lifestyle.

R4 had received a liver transplant several years earlier and admitted that her perception of kidney dialysis had been heavily influenced by her previous experience of dialysis whilst she was a patient in intensive care, post liver transplant:

"Because of knowing about liver transplantation, because when I had that done I was in intensive care in London, I can remember being on dialysis and I have this awful images in my mind of the dialysis machine.... So I have a real fear of dialysis."
(R4, sister, 1st interview).

Most participants acknowledged that their views and concerns about dialysis were largely influenced by their perceptions of dialysis units and, in particular, dialysis patients:
"I remember when I visited the dialysis unit and saw the people watching television, I thought I don't want to end up like that.... I never thought I'd be able to do it. Because when I was talking about dialysis and talking about kidney failure and I saw kidney patients I used to think how pathetic they are. How being so kind of passive and not active and I thought god I don't want to be like that. That's why I want the transplant, but I have been like that and I am still like that some days."
(R4, sister, 1st interview).

However, some recipients who were on CAPD explained that they had now accepted it, although often grudgingly, and had managed to incorporate the regime into their lives. Some also said that although they didn't want dialysis at first they did feel much better once it had started:

"Once I'd had it I wish I'd had it ages ago because I felt so much better. But I wasn't going to have it you know (laugh). It was the principle of the matter I wasn't going to have it (laugh). Within the first month with the routine I felt so much better I was thinking, oh I wish I'd come here earlier (laugh). And everything was a lot better. I did really notice a dramatic improvement the first month. Everyone at work said you're the best you've ever looked (laugh), which was upsetting (laugh)."
(R6, husband, 1st interview).

Those on dialysis spoke about their experience and the general demands of the dialysis regime and how it had affected their, and their families', lives. Some recipients were able to dialyse at home whilst others were dialysed in hospital. The dialysis regimes often varied but each recipient generally had several sessions a week (usually 3 or more), with each session lasting a few hours (around 4½). One recipient (R9), on home dialysis, dialysed at night time because he found that this suited his lifestyle better than daytime sessions. However, each night time session took about 10½ hours, which generally meant that he had to be in bed relatively early to fully complete each session.
All of the dialysis regimes took up a substantial proportion of the recipients' time and, subsequently, impacted on the lives of all concerned. For example, the time each session took up often affected the participants' ability to do other things like socialising, shopping and working. One participant explained how he was no longer able to lie down in the bath to relax (which he enjoyed doing) because he had been advised not to get his peritoneal cannula site wet (to minimise the risk of infection). Others spoke about the practical difficulties of regular dialysis sessions and how this limited their ability to travel, especially abroad.

However, whilst most of these recipients admitted that dialysis had caused varying degrees of disruption to their lives, all had eventually managed to minimise this by re-arranging their lives around it. Many of the participants were still physically able to work and one recipient, a self-employed accountant, explained how he had arranged his work around his home dialysis sessions:

"Yeah it's all right. Because my office is only a mile and half up the road I come home for lunch, which is quite handy. You can make life far less disruptive. I knew I was going to have to do something lunchtime, so I made a point of having a lunch hour and not working through. So the shock to the routine was fairly minimal, I'm fairly organised in that respect, but it just meant coming home to dialyse and the staff knew so it was no great shock to them. The only thing is I've got to do it everyday now... if a client wants to see me and I've got to travel any great distance I plan to see them on the front of the morning as opposed to the back of the morning. You just have to be a bit more organised that's all."
(R10, husband, 1st interview).

Some participants had also experienced several problems with dialysis, some more serious than others. For example, abdominal discomfort and pain whilst on dialysis, indwelling peritoneal line infections of varying severity (some requiring hospitalisation, removal of the infected line and intra-venous antibiotics) and peritonitis:
"One particular time when my husband had come to pick me up I felt really funny, light-headed. So I lay back and in fact my blood pressure was rising instead of falling and when my husband came I couldn't talk and I couldn't coordinate my hands and feet. So they thought I'd had a mini stroke and I had to have an ambulance to Exeter and they did an MRI and thinking I had actually had one. But after about 24 hours I regained the power of speech. But that was actually very traumatic because I was conscious and knew what was going on all the time but I couldn't communicate at all. It was frightening not being able to talk and to think am I having a stroke, what is it? Or is it just a bad infection?

Eventually they found it was a disequilibrium something (a problem with fluid/electrolyte balance, post dialysis). They managed to work out how to deal with it. But it happened again last week. I drove myself to dialysis and came home and I collapsed and felt my blood pressure was rising. And no one was here so I managed to ring 999 and he came back and found me lying and not able to talk again and totally lifeless. And it's that kind of shock, unexpected shock when he'd left me quite fit.

And apart from that the line became infected. They put in another one but that didn't work. Then they put it in another one. But every time things like that happened it meant a long stay in hospital. And this last infection I had 7 weeks ago I've never felt so ill in my life (laugh). I mean I felt fine the night before but woke up unwell. You get to know when you're not well and my temperature shot up extremely high. And when that happens the feeling of complete fear is, what's happening to my body"?

(R4, sister, 1st interview).

Whilst some recipients were able to recognise the benefits of dialysis, most realised that it was not a cure, nor was it an ideal long-term solution to their renal failure. Some recipients also admitted that their time on dialysis had confirmed to them that a renal transplant represented their best treatment option, especially if they had experienced problems whilst on dialysis. However, some recipients admitted that they were only really able to properly consider a renal transplant once they had come to terms with their condition.
5.5 Coping strategies

All recipients discussed how they coped with their illness and all participants spoke about how they were coping with the prospect of the impending kidney transplant. Various coping strategies were utilised by the participants. For example, one family (F11) explained that they used humour to help them through the process, which, after interviewing them, I can testify to. Another family (F9) explained that they were able to cope reasonably well with the recipient’s condition, largely because it had progressed so slowly that they had been able to gradually adapt to his illness and the associated changes.

However, a common strategy used by many recipients to help them cope with their condition was to be resolute and defiant where possible. Many spoke of ‘not giving in’ to their illness and/or trying not to let it affect their lives too greatly. Several recipients spoke about ‘trying to get on with their lives’ as best as they possibly could, despite their illness:

"When you're physically really, really poorly the human instincts arise. It's incredibly powerful. So when I've been lying in hospital with raging temperatures and feeling as if you can't possibly feel worse.... When you recover there's a massive sort of strength, there's a human instinct not to give in, to fight against it and that is very, very strong.

I think that is the energy that I normally expend on other things. It's mind over body (laugh). The psychological side of it is extremely important.... And as long as you can retain some positive mental energy I think, that's what you need. The psychologist said they find that with renal patients. They do get a kind of resilience. But you have to, you have to be so adaptable, because you can't cope other wise. And learning that I think is the most important thing in the world."

(R4, sister, 1st interview).

Some recipients tried to maintain a positive attitude and tried not to worry too much about their illness, treatment or things that they had little or no control over
such as the progression of their condition or what might, or might not, happen to them in the future. These recipients generally felt that if they overly concerned themselves with their condition, future possibilities, or continually felt sorry for themselves, it would only serve to make them more miserable and depressed about their predicament:

"I don't tend to worry.... From where I am my aspect of this is, I've got this, I can't do anything about it except what we are doing. I've got no alternative.... The only things I tend to worry about are the things that I can do something about. If I could do something about it I'd worry about it, but I can't so I've just got to accept it...."

(R9, husband, 1st interview).

R4, who was on peritoneal dialysis, employed additional coping techniques. At the time of the first interview she had experienced several significant problems whilst on dialysis and, at that stage, was in relatively poor health. Therefore, to effectively cope with her situation, she tried to avoid dwelling on things that she could no longer do, because of her illness, as she believed that doing so would only make her more depressed. Instead, she 'reduced her expectations' of life and sought enjoyment from other, less demanding activities:

"I play the double bass but I haven't had the stamina to do that or to play in orchestras and bands, where I had a social life. And to survive, and to cope with it I've just had to block out all the kind of things.... I used to go swimming but now I can't because I had a line in and haven't had the energy. But I actually love music, so I just have the radio and even when I'm too tired to read or watch television I've had music and that's the kind of thing that's kept me going....

But the way I try to think of it is you do cope, you have to cope, there's no alternative.... Not thinking too much about thinking, I wish I was doing this. If you start doing that it becomes crap, so I've learnt to enjoy music and do things in the garden, which I would think when I'm really well again, god what a sad case. But when you're in the situation that's what you do to survive and when you're actually that person doing it doesn't seem so bad. So, yeah, reducing expectations."

(R4, sister, 1st interview).
R10 adopted a similar coping mechanism. He too had come to realise that there were certain things in life that he could now no longer do or seriously consider. Consequently, to cope, he learnt to build his life around his condition and accepted that certain things were, currently, no longer a viable option for him:

"And I suppose to some extent, without making life too difficult for yourself, you do build things around the knowledge that you've got this thing.... You don't ever think about going to live in Spain or whatever, things like that. You think well that ain't an option so I don't even consider it. Not that I think it would be a major consideration in my life anyway, but things like that you kind of discount."

(R10, husband, 1st interview).

Some recipients found that the prospect of a successful kidney transplant particularly helped them to cope with their condition. The transplant was a source of optimism, which they felt offered them the most realistic opportunity to return to a reasonably normal lifestyle:

"But all the time the transplant has been a kind of beacon of hope. Things have happened and things have gone wrong and it's been awful, and I've got better and there's still a possibility of a transplant and that's what's keeping me going, because that's what I want, and I'm very fortunate that my brother's doing that. But it's what's kept me going and what the hospital are actually offering, has really been something that has helped me cope with what I've been through. If I thought that this was going to be my life for the rest of... I wouldn't be the same person."

(R4, sister, 1st interview).

A common coping mechanism used by most participants was to break the process down into stages, or 'smaller chunks'. For many, this made the process more manageable and easier to deal with than if they considered everything, including possible future scenarios, simultaneously. For example, one family (F6) learnt to deal with the recipient's (R6) renal failure before they could properly consider dialysis. It was only once they had accepted the necessity for dialysis that they could properly consider the possibility of a kidney transplant.
However, by far, the most common coping mechanism used by participants was a ‘cross that bridge when we come to it’ approach. Most participants knew what might go wrong in the future with the transplant but most tended to put these issues to the back of their minds. These participants explained that they would only really deal with any such problems if and when they arose:

"But I think we are coping with it pretty well. But we have been both guilty I think of heads in the sand approach to it, until we've needed to come to the obstacle, the next hurdle and then we cope with it and move on. But we try not to worry too much about what's in the future, or about things that may never happen."

(R7, husband, 1st interview).

D10 said that she coped with the impending transplant through the experience of a much older woman who used to go to her salon for a haircut and had donated a kidney to her daughter almost two decades ago. The donor said that this older woman inspired her.

5.6 The decision making process

All participants discussed, in some detail, the decision making process involved in the transplant and the multitude of issues that arose as a result of this. All donors discussed how they reached the decision to donate a kidney, what this process was like for them and the factors that motivated them to make the decision. Conversely, all recipients spoke about their decision to accept the donor's offer of a kidney transplant. All participants also discussed their feelings and concerns about this process, the impending transplant and what effects, if any, this had on their relationships with each other.
All donors initially made an instantaneous, voluntary decision to donate, generally with very little, or no apparent period of deliberation. The donors’ decision to donate was usually made soon after, or on hearing that the recipient required a kidney transplant; a situation they were made aware of either by a health professional, usually a doctor, or by the recipients themselves. However, nobody asked the donors if they would like to consider donating a kidney; it was a decision that they all made for themselves, and none complained of any direct, overt pressure from the recipient, any other family members or health professionals to do so:

“I just made that decision on the day doctor said to me...I never flinched. Once I made up my mind, well I made up my mind straight away, that if that was a possibility then there was no reason for me to doubt. So for me if this is an answer to the problem then I don’t have to think twice about it.”

(D5, wife, 1st interview).

All donors felt that the initial decision to donate was relatively easy to make. Furthermore, at the time they made this initial decision, most donors felt happy with the decision and making it did not significantly trouble them:

“I didn’t have to think about it.... It’s hard to explain really.... It was just a natural thing. I didn’t sort of think shall I do it or not, it was just, yeah I’ve got two, take one. I’ve always been there for the kids no matter what they had or what they’ve done.... And I feel now exactly the same as then, you know. I’m not worried about it, I’m not concerned about it. I know it’s going to happen and that’s about it really.”

(D11, father, 1st interview).

Several donors remarked that family and friends had commented how ‘brave’ they thought they were by agreeing to donate a kidney. However, none of the donors regarded their actions as being in any way heroic or extraordinary. They all just saw it as a natural decision and thought that, given the choice, most
people in their position would probably do the same. They also explained that
their decision to donate was made on an informed basis, in that they all
acknowledged that they were aware of the risks attached to donating:

“Well I’m fairly sanguine about it. It doesn’t exercise me a great deal,
I’m fairly philosophical about it.... Whatever risk is involved is certainly
worth it in my view... and there’s nothing really that over-exercises me
about it. I regard the risks as being fairly minimal, but if the risks were of
a different magnitude I’d probably go through with it, regardless really. I
think if you want to you do and that’s it. So for me it was never really a
what if.... So I don’t worry much about it. To most folk it’s a very unusual
thing, to me I think it’s just fairly matter of fact. It’s something that I want
to do. It’s a practical arrangement, its nothing special. I think most
people in my position would probably come to the same view. So I
haven’t laboured or tortured myself about it, it’s just common sense
really, which is probably why I don’t need all the reassurance....”
(D3, husband, 1st interview).

Some donors (mainly spousal) said that when they volunteered to donate, they
were not entirely sure if they would be able to do so, mainly because they
suspected they would not be a close enough genetic match. All were surprised
and delighted when they found out that they could donate, and none expressed
any disappointment at this outcome.

However, the decision making process was not this straightforward for every
family interviewed. Disparate accounts were described by three donors, who, for
a variety of reasons, had slightly different decision making processes. D6
explained that her decision making process had been complicated by a number of
different factors. Firstly, when the subject of renal transplantation had first been
raised with her husband (R6), he had not yet come to terms with his renal failure
and, consequently, was not ready to consider a kidney transplant at that stage.
Also, around this time, the transplant centre they were initially referred to (not
the hospital where this study was based) was experiencing some ongoing clinical
problems, which eventually led to their live kidney transplant programme being suspended. This led to a crisis in confidence and a reluctance to want to be considered for a transplant at that centre.

The decision making process was complicated further by the fact that R6’s brother had originally volunteered to donate his kidney. They all, especially D6, felt that he would probably be most suitable because they were genetically related and, hence, likely to be a closer genetic match than D6. However, this proved not to be the case as the brothers were different blood groups. D6 had concerns about donating because she and R6 were not genetically related. She therefore thought that she might not be able to donate, and was concerned as to how successful the transplant would be and how long it would last. She hesitated at first because no one had really explained this issue to her, although when this was explained to her by her physician she readily volunteered:

"When they mentioned about live transplantations his brother was obviously the most likely choice, I said, oh I’ll have bloods as well because I thought in the future that will be there. And then when his brother wasn’t compatible and I was, I didn’t jump in because I was worried about the tissue typing and everything. I must admit I asked the transplant coordinator, you say I’m compatible but my tissue typing doesn’t match, that doesn’t really make a lot of sense to me, really for ages. Not until I spoke to the surgeon did I speak to anyone who was quite confident about that and seeming to think that that really wasn’t too important and that you could have very successful transplants regardless of that. And I think I would have probably been more pushy about having it done a while ago if somebody had been a little more positive about it.”

(D6, wife, 1st interview).

Another donor (D10) explained that her decision making process had been affected by the fact that her eldest daughter, like her husband to whom she was donating, also suffered from polycystic kidney disease. Whilst her daughter currently had normal renal function, D10 was aware that, at some time in the
future, she would also probably require a kidney transplant. This caused a dilemma for D10 because she was not entirely sure if she would be able to donate her kidney to her husband (because of her concerns that, as they were not genetically related, they may not have been a close tissue match) and because she was positive that she would probably be able to donate to her daughter because they were genetically related. She knew that by donating to her husband, she permanently excluded the possibility of ever being able to donate to her daughter in the future:

"To be honest it is something that I’ve got a problem with because, my oldest daughter has got polycystic kidneys. I’ve always, in my mind, thought that I’d be doing it for her one day. I never even thought it was a possibility, you know, he’s my husband we’re not brother or sister, so it never even came into it. I did mention at the time to the doctor that I thought I’d do it for my daughter and she said well go ahead and help your husband because by the time your daughter comes round to this you will probably be too old anyway. But it is something that I have a bit of a problem with because I feel a bit guilty because I’ve always in my mind thought that I’d be doing it for her. So it’s something that I’ve always thought that I’d be doing one day, possibly.

No, straight away when the doctor said about the possibility of living donor and my words were it goes without saying but I’ve always thought that I’d be doing it for my daughter. So no there was never any... going away and thinking about it. My only concern was the fact that I’ve always... had it in my mind that I would be doing this, but I thought for my daughter not for my husband."

(D10, wife, 1st interview).

However, her dilemma was eased somewhat by the fact that her youngest daughter, who doesn’t appear to have the same condition, has said that if her older sister needs a transplant in the future she would donate, if she was medically able to.

The only other exception to the relatively straightforward decision making process was a brother to sister donor (D4). D4 initially made an instant,
voluntary decision to donate after his other sister had volunteered to donate.

However, she was found to be medically unsuitable at a relatively late stage in the work up process. This left both sisters, particularly R4, disappointed and upset and D4 said that this probably influenced his decision to donate.

He explained that his initial decision to donate was entirely spontaneous and perhaps a little hasty, largely because of the situation. He subsequently spent the next several months deliberating about whether or not he had done the right thing, and whether he would actually be able to proceed with the transplant if he was found to be compatible:

"I suppose at that time my reaction was probably a little bit knee jerk and it was perhaps a little bit passive in that I thought, well I'll put myself forward to see if I'm compatible. I suppose it wasn't a full commitment at that stage. And then it was probably 3 months after that not quite committed decision that I became aware through the test that I had that I was a compatible donor. And in terms of big decision thresholds the initial one was yes I'd like to be considered and then the next decision is a sort of a change in circumstances, a change of awareness I suppose. I'm no longer a possible, potential donor, I'm compatible....

The first 2 or 3 months... really undergoing a sequence of tests. At the end of each phase of tests you'd sort of pass a milestone in your compatibility testing, and I think that quite an important stage, it's very sequential, and quite structured and at the end of it. And it kind of gives you 3 months of... consideration time before you even know that you are compatible. And that's probably quite useful. And then a slightly unnerving time when you know that you're compatible and then it's really sort of... I don't know I suppose I had a month or two of feeling a little bit oh, unsettled by it, because it became much more a reality at that stage....

But at the time it was a slightly passive decision and that sort well I'm a willing to be tested for it.... At that time I thought well I'll have the tests in 2 or 3 months time I might not be compatible in which case I can't do anything more about it. If I'm compatible then I'll make a decision and that was my thoughts at the time."

(D4, brother, 1st interview).
D4 also explained that as it started to become clear, during the work up process, that he was likely to be a compatible donor for his sister, the more it raised his family’s expectations and the happier they became. However, this inadvertently increased the pressure on him to donate, which he found quite difficult at that stage, because he was not yet entirely committed to the transplant. He felt guilty because of this and a little resentful of the fact that family members assumed that he was committed. At times, this led to D4 avoiding some of his family, particularly R4 and her husband while he decided what to do.

However, like every other donor, after several months of deliberation, he eventually reached the decision that he was in fact doing the right thing and was more than happy to proceed with the transplant:

"...I’ve spent enough time thinking about it to know, to have decided that I want to do it. I came to the view that it was the right thing to do. Because I reached a firm conviction that it was what I wanted to do and that it was the right thing to do. But there was a period of a couple of months where I suppose I was a bit unsure."
(D4, brother, 1st interview).

All donors expressed a determination and a commitment to donate a kidney to the recipients and many explained how disappointed they would be if they were no longer able, for example on medical grounds, to proceed with the transplant.

Several key motivating factors were cited by donors as reasons for them volunteering to donate a kidney. However, the primary reason for donating, in every instance, was to help restore the health of the recipient:

"Well it’s just this thing that I can do. I can give my daughter a kidney and a new lease of life. I should imagine anybody would want to do that."
It's simple, there's nothing deep about it at all, to me it's just a simple matter...."
(D8, mother, 1st interview).

One spousal donor (D2) was also donating his kidney to his wife because she had been so good to him over the years that he felt it was time to somehow 'repay' her for what she had done for him:

"She's looked after me for 30 years... so (laugh)... yeah, time to repay...."
(D2, husband, 1st interview).

The other main reason for donating a kidney, which was only found in spousal donors, was a desire to restore the recipient’s health, not just for their personal benefit but to also help restore their life together as a couple and/or as a family.

All spousal donors donated for this reasons and some felt slightly selfish about it:

"If my wife is in poor health it means that we won't be able to do the things that we want to do.... Plus of course we've only been married for 3 years, so there's a lot that we want to do. And this is sort of the big black cloud on the horizon.

If you love somebody and that person is going to be ill, I suppose you could regard it as a very selfish perspective, we will not be able to do the things that we enjoy doing, if she's ill. And if I can help her from becoming ill so that we can continue doing what we like doing well that's practical. (Laugh) You can call it selfish but that's the common sense approach that I take."
(D3, husband, 1st interview).

Although most recipients had various concerns about the impending transplant (discussed in more detail later), all felt that it offered them the best treatment option for their condition and it was primarily for this reason that they wanted a transplant:

"...I think that I'm going to go on forever, which I know full well is not right, which is why we want this transplant...."
(R1, wife, 1st interview).
Recipients also recognised the benefits of a successful live kidney transplant, especially compared to other forms of treatment such as dialysis and cadaveric transplantation. For example, improved health and quality of life, greater graft survival rates (compared with cadaveric transplants) and increased independence, free from the confines of their condition and dialysis. Most spousal recipients also recognised the benefits that a successful transplant offered them and their partners. These were therefore also significant factors in recipients wanting a live transplant:

"It works both ways... and I think both of us see it, really, as an investment in our future because, this is our second relationship, for both of us, and we’ve been together 9 years now, and we’d like to have as long together as we can, with both of us in reasonable health. I mean everybody says that don’t they? And it’s not given to everybody to have the chance to make that happen. So I think both of us feel that it is something that if he’s able to do it, it’s an investment in both our futures, not just mine. Because life can be pretty miserable for him if I’m having to have dialysis 3 or 4 times a week...."

(R3, wife, 1st interview).

All recipients were appreciative of the donor’s offer of a transplant (this is explored further in feelings and concerns), but most were initially reluctant, and some very reluctant, to accept the donor’s offer. The primary reason for this was because they did not want to have to put the donor through an invasive surgical procedure that carried risks but offered them no physical benefits.

However, all recipients had discussed this matter with their donor and were reassured by them that it was something that they wanted to do, despite the potential risks:

"No major concerns about it, other than when [D8] offered to give me her kidney.... It’s not that you’re ungrateful about the offer but I must be honest, I didn’t really want her to go through an operation so I was quite reluctant. But... we talked it over and eventually decided it was probably
the best way forward and reluctantly, but gratefully, I’ve had to accept this kidney (laugh)...."
(R7, husband, 1st interview).

Most recipients emphasised that they had not pressurised their donor in any way to donate, or even asked them directly if they would be prepared to donate a kidney. In all cases it was the donors who had volunteered to donate. Some recipients also explained that they could never really ask someone to donate a kidney to them because they felt it would be like begging and would put undue pressure on the potential donor. They wanted donors to donate because they wanted to, not because they were asked to do so:

"...It’s not something that you could bring up. I wouldn’t go to my cousin or whatever and say do you want to give me a kidney...? I could never ask for it, I mean my brother offered before I even mentioned it. As soon as he knew I was on dialysis, he offered it. I think that’s a good. I think its pressure isn’t it? You know if you offer it, if something’s asked you feel like they’ve ganged up on you. If my brother didn’t offer and I’d asked my mum and dad and everyone else I think it wouldn’t be their decision, it would be everybody else’s and they’d think, oh I’ve got to really."
(R6, husband, 1st interview).

Some recipients also said that they could only ever accept a kidney from certain people. For example, several recipients explained that they would never willingly accept a kidney from one of their children, even though some had offered and all were over 18 years of age, because of the risks involved and the child’s future health and wellbeing. Others felt that certain people would donate ‘conditionally’:

"I’ve said there are only some people that I would accept a kidney from because I’m very reluctant to be put in a position where I’d feel beholden. And like my mum, and I have another brother, who for whatever reason it would always be hanging over my head in a way.... But my sister and with [D4] I know that with both it’s a genuine offer with no strings
attached. I explained to him when we were talking that I would accept the gift from him because I felt very close to him."
(R4, sister, 1st interview).

All recipients recognised what the donors were doing for them and were grateful for their actions. However, most took the time to explain that they would also do the same for their donor if the roles were reversed.

5.7 Feelings and concerns about the impending transplant

All participants discussed their feelings and concerns about the impending transplant. Some said that the transplant, and in particular the operation, held little or no fears for them and that they were reasonably relaxed about the whole process. However, some other participants confessed to feeling a little stressed, anxious and/or apprehensive at times about the transplant. D10, who explained that her eldest daughter might also need a kidney transplant in the future, said that she had mixed feelings about the transplant, which ranged from nervousness to feelings of excitement:

"It's a really strange situation because you don't want to do it but you do, or at least in my situation it is. But I am scared (laugh), I'm a worrier, I'm a born worrier. I could worry for England .... I must confess that I've had to go to the GP and get something to help me sleep because I was getting to sleep but then I was waking up at 3 and then I couldn't get back to sleep.... I am a bit nervous and a little apprehensive... but surely I'm entitled to be apprehensive?

I can remember when we got the results from the tests and I'd passed and I must admit I was amazed because I didn't think I was that fit, but I was amazed and I was surprised by my reaction because I was really excited. I couldn't wait to get on the phone and tell the daughters and ring my mum and I was really excited about it. And last Tuesday, just for a second at work, I felt excited, it didn't last long but I got a wave — I do get waves of feelings. Some days I can be really positive and I'll think come on let's get this over with and then other days I'm like, oh let's put it off a bit longer. So it's just waves of emotions really."
(D10, wife, 1st interview).
She had discussed her feelings her husband and his family (particularly her brother-in-law who also had polycystic kidney disease and had had a cadaveric renal transplant a year earlier) during a family get-together. However, she felt that they were dismissive of and insensitive to her thoughts, concerns and feelings.

Furthermore, she felt that her husband’s family were treating her like a means to an end and were generally unsupportive and unappreciative. They rarely enquired how she was, although always enquired how her husband was, and her brother-in-law questioned her desire to donate when she confessed to feeling a little nervous. This made her question her own feelings and consider if it was normal for her to feel this way:

“They make me feel like a piece of meat.... One day we had a family lunch around August and I was saying about being nervous and he looked at me and said well perhaps you shouldn’t be doing it then and I thought that was a bad thing to say, because surely I’m entitled to be apprehensive? But then again because of him saying that you start thinking, oh dear, you know, am I normal? You see, I’m the well one and this is a breeze for me and I don’t know whether they fully understand that it is a big operation.”

(D10, wife, 1st interview).

All recipients readily acknowledged that volunteering to donate was ‘a big thing’ and all felt grateful to the donors for this. Some recipients found the donor’s offer of a transplant ‘breathtaking’ and some confessed to being ‘blown away’ by it. Some also became emotional and tearful when they discussed this matter:

“I think it’s a big thing for him, you know, and I keep saying if you back out I will never hold it against you. And he said I’m not going to back out I’m going to give you that kidney .... So, yeah I mean, he’s been very good actually. I mean, for him to do that, I think, is a big thing.... Though he’s my husband I know some husbands wouldn’t do it for their wives and, you know, I think a lot of that. I think well he must love me (laugh).
At this stage she became tearful, but did not cry.

*I get a bit choked some times... because he's prepared to do that. I think it was wonderful really. I think it's marvellous...”*  
(R2, wife, 1st interview).

Family 8, a mother to daughter donation, explained that they felt quite clinical and matter of fact about the impending transplant. Whilst R8 was thankful of her mother’s offer to donate, she felt that trying to keep their emotions in check was the best approach for them:

“Mum and I are a bit strange, we don’t want to have any emotional involvement with emotions at all. We see it very business like. If it works it works and that’s great, if it doesn’t it doesn’t, and we’ve sort of said that we don’t want great big long conversations about it and it’s just going to be done.

And we haven’t discussed, apart from the mechanics of it, anything else. I think that’s just the way we are. I think because we see it as we don’t want to put emotion on it because if it doesn’t work then that brings up all sorts of problems. You know, you feel guilty that it doesn’t work, and I would feel guilty that I’d taken a kidney and that sort of thing and we just decided that that sort of emotion is very negative, you know, it can’t do anything for us. And we are always positive but if that happened then we just have to leave it and move on. So there’s no point in doing this and soul searching about it.”  
(R8, daughter, 1st interview).

Some recipients explained that they wanted to somehow ‘repay’ their donor for their actions when they were well enough to do so. None mentioned repayment in a monetary or material sense but R1, for example, mentioned wanting to repay her husband by helping him out more with their business when she was better.

Another donor (D7) said that she and her husband had discussed the transplant so much over the last couple of years that they had now reached the stage where they were ‘sick of talking about it’ and now just wanted to ‘get on with it’.
Most participants were optimistic about the transplant and had invested varying amounts of hope in it. Many saw the transplant as ‘a light on the horizon’ or a ‘beacon of hope’ – hope that the transplant would improve their health and their life afterwards:

"My second eldest brother had a transplant a year ago last November so, to a degree, I can draw on his experiences. The one thing that he comes up with is you’re going to feel much, much fitter.... I don’t know how I’m going to handle it if I don’t, but at the moment I handle this situation with optimism. I look forward, I’m planning to go on some proper walks once I’m fit."

(R10, husband, 1st interview).

However, D10, who had mixed feelings about the transplant, explained that even though her husband was positive and optimistic about the transplant she was concerned about being overly optimistic just in case she ‘tempted fate’.

Although most participants, particularly recipients, were quite optimistic about the impending transplant, all confessed to having some concerns about the process. Common concerns related to a number of issues pre, intra and post operatively, the transplant and the post-transplant period. Two donors had been concerned about the testing procedures involved in the pre-transplant work up process. They were both primarily concerned with the possibility that a physical abnormality would be discovered during this work up process and the potential implications that this would have for their own health and on their ability to donate:

"I suppose my sensation is feeling a bit like a guinea pig and hoping like my 24 hour urine test turns out ok. It’s not that I’m over anxious about it, it’s just that every loop and hurdle you go through and every test you think is this going to be ok?

They do tell you that as a potential live donor we’ll give you a thorough run through and we’ll probably find things to tell you about that you wouldn’t be aware of. One of the things that they found on me was a cyst on my liver... which I wasn’t, probably because of my nature, overly
alarmed, certainly because most people said it’s probably nothing. But at the same time my brother-in-law was dying with liver cancer....

So there was a bit of angst about wanting your results to be sound so that you can go through with it, but then that’s about the only trouble ....” (D3, husband, 1st interview).

Three families were concerned that problems would arise in the run up to the transplant, which might possibly result in the operation being postponed or cancelled. R11 was concerned that his transplant would be delayed by an infection. The other two families (F7, F4) had already had their original transplant date postponed before the first interview.

Family 7 had their initial operation cancelled the week before transplantation because the transplant centre had not received the required written confirmation that their genetically unrelated transplant could proceed from ULTRA (Unrelated Live Transplant Regulatory Authority). This problem was blamed on a postal strike that was ongoing at the time. Both participants expressed how angry, disappointed and upset they had been at the time because of this and, even though written confirmation from ULTRA had been received by the time of the first interview, they both said how the situation had compounded their concern, albeit mild, of a further possible postponement.

Family 4 had also experienced a postponement of their original transplant date because R4 had developed a serious line infection in her PD cannula. Both R4 and D4 explained how difficult the postponement had been for them. They were concerned that the new proposed transplant date might again change if the recipient contracted another infection and both found this uncertainty unsettling:
"We were a month away from when it would happen, and my brother’s all geared up for it and we’re all getting really psyched up for it. And then told, no it’s going to be 2 months. I take the view, I have to, ok fine I’ll deal with it, carry on, but from past experience my husband thinks for Christ sake what is going to happen between now? Theoretically, they want you to be stronger and better, but because of what’s happened in the past with line infections and delays. What happens if your fistula gets infected or by the end of November something else will have happened and it will be delayed again. So it’s almost like a carrot being dangled....”

(R4, sister, 1st interview).

The most common concerns were related to the actual operation and/or the transplant itself. Virtually all participants, particularly recipients, were concerned about the other participant’s well-being in the process. All recipients were concerned that the donor would be harmed, would suffer, or even possibly die because of the transplant and this worried most of them greatly. Some recipients were so concerned about the risks to the donor that they would have preferred to have received a cadaveric kidney transplant.

However, most recipients had been reassured about the transplant by the donor and/or health professionals (usually a doctor). Donors had reassured them that they really did want to proceed with the transplant, whilst health professionals had pointed out to them that the major risks involved in the procedure were relatively minimal and that that a live kidney transplant offered them many benefits:

"The only worry I’ve got is if anything happens to him by doing it. I know if anything happens to me I’ve got to have the operation, it’s for my benefit. But with [D2], he’s having an operation he doesn’t really need. He’s doing it for me.... And that is the only thing I’m bothered about, to be honest. I know they said it’s a very small risk that he’s taking, but, it’s still that risk. That’s why I’ve got a bleeper if one came in (a cadaveric kidney). I did say I would take that one rather than my husband go through the operation. But he wants to do it.... He said don’t think I’ve had all these tests for nothing now, he said I want to do it (laugh)...."
He said I will do it. And I said no you won’t. He said yes I want to do it. If we’re compatible if it’s ok if I have the tests, everything’s all right, I want to do it. And the doctor was there and he said well are you sure about this and I said well we need to talk about it and he said I tell you what I’ll send you down to talk about it with the surgeon and we’ll see what you think. And I did feel a bit better about it after speaking to the surgeon, about it....

I was worried about the problems my husband might get, you know. He obviously wouldn’t do it if he wasn’t fit, but I was thinking if anything happens to him by giving me a kidney, I would never forgive myself. That is still in my mind a bit.... I’m getting a bit better about that now. We’ve talked about things but that’s the only time I feel a bit sad about it is [D2] having to go through it. Not myself because I know, I mean I hope nothing happens to myself, I’ve got grandchildren and everything. We all want to live but I would be more concerned about my husband because I need the operation, he doesn’t....”

(R2, wife, 1st interview).

Some participants said that their family members were also concerned about the transplant. This was particularly the case in spousal transplants where those family members expressing concern were usually the participants’ children. They were mainly concerned about their parents going through the process at the same time and the possibility that something would happen to one or both of them during or after the operation. These participants had reassured their children about the process, and health professionals, particularly the live transplant co-ordinator, had also helped in this matter.

The other most common concern expressed by virtually all participants was whether or not the kidney transplant would be successful and how long the transplant would last:

“It’s a big worry for me if it doesn’t work, not so much for me but for [D6], you know, giving it. That’s what they say on the talks, they say psychologically if she gives it and it doesn’t work she could be upset. So we went through all that. I think it was more talking about if it didn’t work, because we know all the good sides if it works. Like I said before
my wife is pretty quick so she knows what's involved. I think things will be better for me not worse, but in the back of my mind I'd hate it that she wants to have to give it and it won't work. That would be the one thing, the worst scenario." (R6, husband, 1st interview).

Some donors were concerned about how they would feel after the operation. For example, would they be in any pain and how many tubes or drains, such as urinary catheters, would they have to endure? D10 also expressed some concern about her future health and well being post transplant with just one kidney.

Other concerns expressed by some of the participants included fear of the post-transplant anti-rejection drug regime, apprehension of follow up care for donors post-transplant (expressed by some recipients), being discharged home from hospital too soon, and concern over work and, in particular, financial matters post transplant:

"The biggest problem's been the business obviously. That's the biggest worry, rather than anything else.... There is no financial help; we're fortunate that our family are grown up. They're not dependent on us... and the fact that we could, we've managed to make up the rent and things from selling the car hire but that was just fortunate, you know, one of those things." (R1, wife, 1st interview).

R5, whose renal failure was iatrogenic, was concerned about his GP's knowledge of transplants and how this may affect him on returning home from a hospital that was several hours away.

5.8 Donor-recipient relationships

Although all recipients were grateful to the donors for their offer of a kidney transplant, most felt that their relationships with each other had not changed as a
result of the transplant, regardless of how they were related to each other. Most donors and recipients maintained that they had been close anyway, before the offer of a transplant was made:

"It hasn't changed our relationship at all really. I can't say we've become any closer because we've always been close.... Sometimes we're more like soul mates, you know.... But no it hasn't affected our relationship at all, other than the physical side of things, which, erm, are just down to me really....

I think it would be wrong to say it's brought us closer together because it would be quite sad if it took a kidney donation to do that (laugh).... But no, we're still very happy and hopefully it will keep us that way." (R7, husband, 1st interview).

However, some of the other participants, most of whom were related by marriage, said that their relationships had improved since the donor had offered to donate a kidney:

"It's quite an emotionally charged thing. You know sometimes you think that it would automatically and forever forge a strong bond between me and my sister. I mean there's a strong bond there and I think it probably has overall grown stronger. I think with the decision to donate, obviously it has a big impact on my sisters at the time when the original operation was cancelled. It gave my sister a big boost, in terms of hoping that her chances weren't completely scuppered. And also that another one of her family was willing to donate, I think it meant a lot. I think for me, at that time, it was quite nice to give that hope and to be able to receive that sort of acknowledgement and affection from my sister.

We've come up for medicals and various things jointly.... You feel a bond, like a team work bond forming and I can see that something that when all this thing is over, which ever way it goes, is something that we're probably going to miss. So I'd say, generally, a close relationship has got closer."
(D4, brother, first interview).

5.9 Transplant service issues

Although some participants were critical of certain aspects of the transplant service, they were all generally happy with the provision of treatment, care, support and information, at the regional transplant centre and other associated
hospitals. All healthcare staff (such as nurses and doctors – particularly the participants’ consultants) were commended by the participants. However, the live transplant surgeon and, especially, the live transplant co-ordinator were particularly praised for their dedication and hard work with families:

"I've said to other people, people complain about the NHS but it's been absolutely brilliant. I can't really fault it. You couldn't pay for the sort of service I've had."

(R9, husband, 1st interview).

However, several participants criticised certain aspects of the transplant service or simply identified areas that they felt could be improved upon. D4 complained that his sister had volunteered to donate her kidney to his other sister (R4), but was subsequently found to be medically unsuitable at a relatively late stage in the process (several weeks prior to transplant). She was, therefore, unable to proceed with the transplant, and he said that this had left her feeling disappointed and upset. Whilst he acknowledged that the transplant centre was very busy, he did feel that his sister needed some sort of follow up care or additional support after this event, but said that she did not receive any.

R5, who lived in the South of England, expressed concern about his GP’s knowledge of renal transplants and the apparent lack of support, information and communication provided to GPs by the regional transplant centre. D6 felt that attending out-patient clinics to collect blood results was an aspect of the transplant service that needed to be reviewed. She questioned the need to attend busy hospital clinics when most of the patients in attendance were genuinely ill and she was fit and healthy. She felt that such appointments could be handled differently, as the current system was a waste of her and their time and also
restricted the amount of time that physicians could spend with patients, who she felt were more genuinely deserving.

D7 felt that the transplant centre needed to explore how they approached families of potential live donors. Whilst she understood the need not to overtly pressurise families to consider donating she did feel that, to improve the number of live donors, the service needed to be more proactive and approach families directly rather than wait to be approached. However, this was not intended as a criticism of the service but rather an area that she felt needed to be reviewed.

R7, whose original transplant was postponed due to ULTRA problems (blamed on a postal strike), explained how much this had unsettled him and his wife and how much it had upset her. He felt the situation could have been handled better, in that he believed the unit had left the application process to ULTRA until ‘the last minute’.

5.9.1 Information needs and the provision of information

Whilst the information needs of participants varied, all were happy with the provision of information during the pre-transplant phase. Most information, for the majority of participants, came from information evenings laid on by the transplant unit (discussed in more detail later). Other sources of information were books, leaflets (often provided by hospitals) and staff, particularly the transplant coordinator and their consultants. Most participants informed me they could, if they wished, phone the coordinator for further information or to ask questions
that they had – and some had done this. Some had also done additional reading themselves, such as, accessing information from the internet.

However some participants did raise concerns about the provision of information. Some felt that it was insufficient, or just adequate, whilst others said that more structured information, particularly in written format, was required. D1 said that she would have appreciated more detailed information earlier on about certain topics, such as dietary restrictions, so that she would have been better prepared for dietary changes. D7 said that she felt more information, particularly in written form, should be provided at an early stage about possible treatment options, such as CAPD and transplants, so that people could be better informed about such choices earlier on. D8 felt that information had not been readily forthcoming from the transplant centre and she said that she had to ask for every piece of relevant information herself. She would have liked to have been provided with more structured information, verbal and written (booklets and/or leaflets) from the start about the likely process and timing of events.

R3, who was a qualified health professional, revealed that she had quite specific information requirements. For example, she was concerned about whether or not the transplant would affect her ability to travel abroad, but her main concern related to her work situation post-transplant. As she would be immunosuppressed post transplant and she would be coming into contact with patients with potential infections, such as MRSA, she wanted to know how safe it would be to return to such an environment and if she would have to take any special precautions.
She explained that her major source of information was her consultant at her local hospital, but maintained that nobody had been able to give her a definitive answer to these questions. This unresolved situation had caused her some anxiety and, on occasions, had even kept her awake at nights. However, she said that part of the problem was down to her because, despite her concerns, she had repeatedly failed to ask relevant questions, despite having the opportunity to do so:

"I wouldn't say that the information that we've had along the way... has been particularly thorough. It's been patchy at best. I think it's the NHS worker's syndrome actually. I feel that I don't want to take up too much time, because there are lots of people who are worse off than me. So I get in and out... and then afterwards I think, oh I wish I'd asked such and such. So I keep on shelving it, thinking, oh well I'll ask the next time, I'll ask somebody else. I have looked on the internet but there's nothing there for people like me. And the information I want...it sounds quite sort of selfish, so I don't ask.

When I ask the Professor questions he answers them very fully. But I'm always conscious of the fact that outside there's another 10 people waiting to see him. And I know, perhaps it's more to do with me than it is with him and, until recently, I only saw him once a year. So you save all your questions up for 12 months, rush in there for 20 minutes and then rush out again (laugh). So it doesn't give you a lot of time ....

So if I want to find something out I've either got to go on the internet, and I'm quite wary about using the internet, because I know some of the information is good and some is unreliable. So if I don't use that I have to track XXX (transplant coordinator) down and she's incredibly busy, or I have to ring the Professor up and those are my options really. The Professor is very approachable, I have chatted to him on a couple of occasions, but he's got a whole load of other people waiting outside.

The transplant coordinator has always said if you've got any questions just ring me up. .... And then again, maybe it's because I'm not demanding enough, I don't know... I don't know the answer to that one. I haven't made great use of them, because up until now I haven't really felt the need to, and I suspect that if I rang her up and said look I'm really worried can I come and see you I'm sure she'd say yes, of course you can, or I'll come and see you. So perhaps that's as much to do with me as it is to do with them. I should know better really shouldn't I''?

(R3, wife, 1st interview).
She also suggested the necessity of up to date and appropriate information booklets and leaflets that were relevant to both donors and recipients.

One family commented that, whilst they were generally satisfied with the level and provision of information, when they did raise what they felt was a legitimate query, it was not well handled by the unit, which left them feeling disappointed, upset and reluctant to ask further questions. Their desire to proceed with the transplant was questioned and this disappointed them further:

"I had heard from other people about keyhole surgery for donors. So just out of curiosity I should ask, because given these potential benefits, we are going to feel a bit like idiots if 2 weeks later after we've had our op someone says oh they are bringing that in now.

So I emailed the transplant coordinator and back came a reply. She quite clearly explained all these whys and wherefores of keyhole surgery. It was enough to persuade me that it wasn’t a very good idea. She said that they did it in Nottingham and Leicester and if we wanted to be referred there fine but these were the pros and cons of it. But I had no intentions of going anywhere else other than there. She finished the email off by saying if you’ve got any doubts, and this is what really stuck the knife in as it were, at this stage I think we ought to know, or something like that. I got cross with that and I’m a fairly placid chap, but I thought I’ve asked one question throughout and the minute I ask a question you accuse me of having doubts. On top of that not only did you put on the bottom of the email an intimation that I’m having second thoughts about going through with it but she copied it to my doctor and the surgeon.

Then I get an email from the surgeon saying I think we need to chat. I knew what he meant but I emailed him back and said chat about what? I emailed the coordinator back and let her know that I had absolutely no doubts and I was purely asking out of curiosity and that she’d satisfied my curiosity and confirmed what I’d already thought anyway. That has now kind of left us in a cul-de-sac because now, even if we have got any questions, we aint going to ask anyone because they might think we are having doubts. The more we thought about it the more angry it made us.”

(R10, husband, 1st interview).

5.9.2 Live donor information evenings

A major source of information for families came from the transplant centre’s ‘live donor evenings’. These are information evenings organised by the
transplant unit (although some families did attend similar evenings at their local hospital, which were often supported by transplant centre staff) at regular intervals throughout the year. The purpose of these evenings are to provide structured, balanced and understandable information to prospective live donors, recipients and their families and to answer any questions they may have.

Each evening lasts a few hours and typically consists of several speakers, such as the live transplant coordinator, a transplant psychologist, a nephrologist and the live transplant surgeon. The unit also invites along several families, who have recently been through the live transplant process, to talk about their experiences.

Most participants had attended one of these evenings and all found them to be informative and beneficial. All participants maintained that the information presented was well balanced, identifying the pros and cons of live kidney transplants, and had just about the right mix of seriousness and light-heartedness. Many also found that having the opportunity to ask questions particularly helpful.

However, all participants claimed that one of the main benefits of the evenings was having the opportunity to meet and speak to families who had recently gone through the live transplant process themselves. Participants felt that this added an extra dimension to the evenings that simply could not be provided by health professionals:

"We've been to a couple of live donor evenings and that's been very reassuring. It's amazing the way they do it because they start off very negatively, and this can go wrong and that can go wrong. You start to feel yourself go down slightly (laugh). But then with having the donors
there and so on, and, and, things start to go up, you come away thinking right lets get on with this (laugh), lets go, you know.

The co-ordinator, gave a talk and the psychologist did, she does the psychological bit, about if it went wrong, you can get to sort of suicidal tendencies and that sort of thing. We had a talk from the surgeon (laugh) and he has everybody rolling around. Then we had about 3 sets of donors and recipients who go out and say their bit. Then we had a break in the middle and got to talk to them and ask questions.

They'd all had their transplants recently and you feel quite sort of bolstered by what they have to say. Everybody sits there thinking, is it gonna hurt? But they said 'a bit of discomfort, not too bad' you know. You feel so positive after talking to them, especially now that they've gone through it, and they're just, well, ordinary people, you know. They've also gone through it not knowing what's going to happen...it gives you a lot of confidence.

We found it helpful... we met this couple the other day who were just starting the process and I said if one comes up go, don't miss it. I suppose really, the evenings have covered most of those things that we've wanted to know."
(D1, husband, 1st interview).

However, although participants generally did find the evenings helpful, some raised several concerns about them. Some families, who lived in the South of England, explained that the distance to the transplant centre was a problem for them and some specifically did not attend an information evening there because of this (although some did attend similar evenings at their local hospital). D7 said that the timing and frequency of the evenings was important for future prospective families. She felt that it was important that the information evenings were held fairly frequently throughout the year so that families considering a live transplant had the opportunity to attend at the 'right juncture for them', thus ensuring that they got the most out of the information presented.

R7 felt it was important that, if possible, sufficient live donors and recipients attended the evenings so that all prospective families attending had the
opportunity to speak to them if they so wished. D4 pointed out that, although the information presented at the evening he attended was well balanced, all of the live transplant families who came along to give talks had all apparently had uncomplicated experiences. He acknowledged that perhaps families considering a live transplant would not necessarily want to speak to families who had experienced major complications, or for that matter that such families would want to talk about their experiences, but he did feel that if the evenings were to be truly balanced hearing about such experiences was important:

"I think you have people that are talking about it and, to varying degrees, the operation has been a success, without complications. I think the information presented was balanced but you haven't got donors and recipients where the process hasn't been successful, or there have been problems. It seems to me that personal experiences are obviously good. And they are very positive and they are quite uplifting to actually meet people who've done it. It's quite a comfort for people who are considering doing it. And I suppose for people who are considering doing it you don't want to speak to somebody where it's not been a success. But I suppose if you're talking about balance then perhaps having... some insight as to where it's not been a success and how people have felt about it then that might give it a bit more balance....

But I think the evening is a very good thing. But, perhaps, just the transplant coordinator might be able to give an account of a couple for whom it hadn't been successful and what the consequences were for that, in terms of the donor and recipient. I mean it's not likely to come from the horse's mouth because perhaps people wouldn't want to talk about it. But she might be able to give an insight. And that might be quite useful."  
(D4, brother, 1st interview).

Family 10 attended an information evening at their local hospital in the South of England. Whilst they found the evening quite useful, they felt that some of the health professionals were not very good speakers, in that some information was presented in a confusing manner (e.g., the risk factors of a particular anti-rejection drug were unclear) and they seriously questioned the suitability of the
live kidney recipient who attended. They felt that more careful planning should have gone into this evening and was certainly required for future evenings:

"Yeah it was ok. Some of the people who gave presentations were not speakers, so that doesn’t help. God bless the bloke who came along. In came this guy with an arthritic condition and it’s not really what you want to see. When they explained it to us afterwards it was very laudable because it was done on the basis of, well if he can do it you can do it, but that’s kind of not what’s going through your mind at that stage. What’s going through your mind at that stage is, I want to see someone in a full vertical position with a big broad smile on their face, colour in their cheeks and think, I’m going to look like that mate (laugh), and maybe a pint of beer in his hand or something (laugh). You just want something that makes you think, yeah this is going to be a really good move. Not someone you are thinking holy cow.

When you get it explained it’s ok but it’s a bit late by then, you know first impressions are everything. The chap was completely unprepared and not really a very good person to put in front of a bunch of strangers because he was quite shy, bless him, and he was not used to speaking and he didn’t have much to say for himself. So it would have been far better if they’d picked someone who was a bit more confident.

Apart from that it answered everything I think. I was pretty convinced I was going to do it at that stage anyway so I was there more for my wife than for me."

(R10, husband, 1st interview).

R9 felt that these information evenings might not be for everybody. He said that he did not want to attend one of these sessions and certainly did not want to meet or speak to other families who were going through, or had been through a similar experience:

"My wife went to one but I wasn’t feeling very well at the time, I had a touch of flu or something, but to be honest I would have gone because [D9] wanted to go. But I was actually ill so I couldn’t go. To be honest they have renal things, it’s almost like a family type thing and there’s something telling me that I don’t want to get involved with all of that.... I don’t know why I just don’t. It’s almost like a sick club and I don’t want to be sick.

I just don’t see what I could get out of it. I mean listening to other people telling me about the problems they have.... I don’t see how that will help me."

(R9, husband, 1st interview).
Most participants were generally happy with the level of support they had received from the transplant unit. Most health care staff were commended for the support they had provided to the participants throughout the process, but XXX (transplant coordinator), in particular, was praised for her work with families:

"The renal service has been excellent. At one point I was talking to the 2 boys, and we were just having a chat about things to come and what will happen and I heard them saying you better learn to drive because what's going to happen if mum and dad die on the table? And I was quite taken aback because our transplant coordinator has spent 2 hours talking to the family. So I thought that all their fears were clarified, but clearly not. So I rang the hospital and said could they get in touch with the transplant coordinator to find out if there was a psychologist who could come and talk to us as a family. But the transplant coordinator arranged to come down to us and as it turned out we eventually went up as a family, and she was absolutely marvellous. She spent 2 or 3 hours going through everything with the boys and really sort of dealing with all their anxieties and really making them feel reassured that they were not going to take me unless I was fit and had passed all the tests. So I think that was a bigger worry for the boys. So they've come away now and I've said how do you feel about it and the first thing they said was they answered my questions. So I think that says a lot."

(D5, wife, 1st interview).

However, some recipients recognised that the transplant coordinator was a very busy person, often with great demands placed on her time. None of the participants criticised her in anyway but they did feel that, as she only worked on a part-time basis, another coordinator was required to help her provide better levels of information, care and support. Some felt that there was also a specific need for some sort of counselling or psychological service to be made available to all of those who wanted or required it. However, they explained that they did not necessarily want a 'formal counselling' service as such, but rather someone they could talk to about their questions, worries or concerns:

"I've got the coordinator's number... she's an incredibly busy person. And she deals with the practical sides of it, and I know my experience when I'm actually there and I know she'll come down with us to theatre. But when we talked to the psychologists I really feel that they need
someone who has more time to deal with... the emotional support. I think there is a definite need for that. Especially for families, maybe not me because I've got mechanisms, but other members of the family... the psychologists were just doing it as a routine thing for my brother and also myself, just to check that it would be in both our interests, but they kept saying actually we don't do this, this is not general practice. We'll talk to you now and you can talk to us again but we don't normally do it as a matter of routine."

(R4, sister, 1st interview).

5.9.3 Shared hospital care

As most participants lived in South West England, their treatment and care was often managed by the transplant centre and their nearest, suitable hospital. Most families managed in this way reported a variety of problems with this 2-centre set up. These included conflicting opinions regarding treatment options (for example, a local hospital questioned the need for and timing of a pre-emptive transplant), which caused confusion and uncertainty in participants, and blood and test results often went missing or were delayed by several months, between hospitals, which often caused problems with consultations.

Many reported communication problems between their local hospital and the transplant unit, such as missing or delayed hospital appointments. R9 reported that he was taken off the cadaver transplant waiting list by his local hospital for one month because he had a CAPD catheter infection. However, they failed to inform the transplant unit when he was supposed to go back on to the waiting list. He had to phone the transplant unit himself to resolve the situation, which resulted in him being off the list for over 3 months instead of the intended one.
Some participants also claimed that there was a certain degree of posturing between some consultants at different hospitals, which many found to be confusing, worrying and unprofessional:

"We found that there's a lot of fighting between the consultants from the different centres. One set of consultants will say, oh what are they doing, and they'll tell you one thing. Then you go back to your local hospital and they say what are they doing, you shouldn't be doing that and they change everything. And as a patient you're stuck in the middle because you don't know which hospital's regime you're supposed to be following (laugh).

When I was here 8 years ago and saw the Professor, he would say you don't want to go to that hospital, they don't know what they are doing. I know what I'm doing, but I'd say well I'm working I can't come here, all this travelling, I need to go somewhere nearer and he sort of said well on your own head be it. He called the other doctor Dr an... evil witch, or something like that (laugh). And she, when she knew I'd come from him, she said oh, he's bearded something, I don't know.

And that's difficult because that makes you slightly nervous about what they are doing. But luckily now the surgeon, and the coordinator I know doesn't rate my local doctor at all, she doesn't like her. But the surgeon here, he works quite closely with her and he quite likes her, so that's alright (laugh)...."

(R8, daughter, 1st interview).

However, family 7 whose care was managed by two different hospitals felt that there had been no problems in being managed by 2 separate hospitals, despite their initial fear that there may be problems with this set up.

5.10 Conclusion

This chapter has presented data from interviews conducted with participants pre-transplant. The next chapter presents data from interviews conducted three months post transplant.
CHAPTER SIX: The interviews: 3 months post-transplant

6.1 Introduction

In this chapter, data from interviews conducted 3 months post transplant are presented. All of these interviews were conducted individually, in private, in the homes of the participants. However, whilst 11 families were interviewed pre-transplant only 9 families actually proceeded to transplant.

Two female spousal donors (D5 and D10) were found to be medically unsuitable to donate very near to their proposed transplants. D5 was found to have an elevated blood glucose reading just prior to donation (her previous blood sugars had been normal, although there was a history of diabetes in her family). D10 was found to be hypertensive near the date of transplantation (she had previously been normotensive in her pre-donation work up). As both conditions are contraindicated under BTS/RA (2000) guidelines their proposed transplants were postponed indefinitely pending further medical investigations.

Both families were extremely disappointed and upset by this. However, I felt that including them in any further interviews would have detracted from the main focus of the study, which, at this stage, was primarily to explore their post transplant experiences. I therefore decided to exclude them from this and the final interview and informed them of my decision verbally and by letter.

The remaining nine participants' experiences have been categorised as:

- Getting ready for the transplant
- The operation and post-operative recovery
- Life after the transplant
- Feelings and concerns about the transplant
When I conducted these interviews, all but one of the transplants had been successful. Family 3 experienced a catastrophic, irreversible graft rejection episode several days post transplant, which eventually resulted in the transplanted kidney having to be removed. Their experiences in the run up to the transplant and immediately post transplant are very similar to the other families and have been categorised accordingly.

However, their experiences from when the transplant failed are very different to the other families. I have therefore formulated a different coding framework for this family from this stage onwards. Their post graft failure experiences have therefore been categorised as:

- The impact of rejection
- Treatment issues and options
- Coming to terms with rejection
- Service issues

6.2 Getting ready for the transplant

Participants recounted their experiences and feelings in the run up to the transplant, starting pre-admission through to their arrival at the operating theatre. In the weeks and days before admission many spent their time organising things at home and work, such as getting ready for admission and getting their work in order ready for their leave of absence:

"I was gearing up for it ...arranging things at work...to hand on... and that actually had quite an impact on my work at that time. It meant that I was busy trying to reach a stage where I could hand things over. So most of November was quite busy, it was quite exciting. I was trying to get my work thing sorted out and, in a way, being busy at work was quite
fortuitous I suppose because it was a good distraction. I wasn’t spending too much time worrying about the operation.

The actual week beforehand was...when it really started to feel real, i.e., the proposed date is now going to happen. So I then had to go and do things like buy pyjamas to go into hospital. So that last week it was starting to feel quite real and I worked up until the Friday and then I had to go into hospital on the Sunday afternoon. I think on the Friday when I finished work I was absolutely knackered because I’d been finishing loads of stuff off and I just came back here and I had a really early night. I had a few beers and then had quite a reflective, contemplative night on my own, which was quite good.”

(D4, brother, 2nd interview).

Admission to hospital was generally uneventful for participants, although some did have to wait several hours for a bed to become available on the transplant admission ward. Recipients were usually admitted to hospital on a Saturday, donors were admitted the following day, with the transplant generally scheduled to take place on the Monday.

Some recipients experienced health problems prior to the transplant. For example, R3 became anaemic several weeks before her transplant, which left her feeling tired and weak and resulted in her taking several weeks off work prior to admission. R4’s general health had also deteriorated in the run up to her transplant. She had become increasingly lethargic and a heart problem was suspected. However, this was excluded following a treadmill test and an angiogram. Her lack of energy was primarily attributed to her renal failure.

R7, who wasn’t on dialysis pre-transplant, lost his remaining renal function shortly after admission to hospital:

“On Sunday [R7] couldn’t pee at all, his renal function had conked out. So we kept busy because he had to have dialysis and the focus was on trying to get him fit for the operation on the Monday. So that was really
busy and a bit worrying because we thought that the operation might be cancelled because we didn't know whether he'd be fit for it."
(D7, wife, 2nd interview).

All of these participants were concerned that their health problems may have resulted in their operations being postponed or even cancelled but all were able to proceed to transplant as scheduled.

All participants discussed how they felt about the impending transplant before they went to theatre. Whilst some were nervous and apprehensive about the procedure, most remained relatively calm and relaxed and maintained that they felt little or no anxiety. No one had changed their mind about wanting to proceed with the transplant and all felt that it was the right thing to do.

However, all participants confessed to having some pre-operative concerns. The most common concern amongst recipients was for the donor’s health and well-being. All were worried about their donor going through an invasive, surgical procedure for their benefit. Some had discussions to establish if the donor still wanted to proceed with the transplant and many also told their donor that it was ok to back out of the transplant, if they wanted to (although none did):

"I was scared out of my pants. I couldn't go to work, my mind was just on the operation. I was thinking what could go wrong. Then I couldn't go to work because I was thinking the worst thing that could happen is dad is going to pop it. Then I'm going to be worse off because I've got his kidney and he's gone. I'd rather have a dad than a kidney.

I wasn't worried about myself because I was gaining everything. It was just dad, I was worried that he was going to die on the operating table and that was my main worry. I know they say it's just a procedure and they've done it so many times but it's still being cut open and anything could go wrong."
(R11, son, 2nd interview).
However, F11 had regular discussions about this matter and D11 constantly reassured his son that everything would be all right and that he wanted to proceed with the transplant regardless of the risks.

R4 said that she was desperate for a transplant because she had been so ill over the past year. But she was concerned that, in the run up to the transplant, her brother (D4) might become so nervous about the transplant he would decide that he just couldn't go through with it. However, she was also concerned about his well being (like all other recipients) and would only proceed with the transplant if he was absolutely sure that he wanted to. She explained that even though she had had a bad year, particularly with peritoneal dialysis, she would rather have stayed on dialysis, even though it had been problematic, than have a transplant that he did not want. They too had discussions, in which he affirmed to her that he wanted to proceed with donation.

On the day of the transplant, donors were taken to theatre first to have their kidneys surgically removed and inspected by the transplant team. Recipients were then taken to theatre some time later when the surgeon was ready to transplant the donated kidney. Many recipients found this difficult and being alone on the transplant ward tended to compound their concern for the donor.

Other concerns included general worries about the impending operation and, in particular, the post-operative period. For example, how would they feel after the operation, would they be in pain, how many tubes would they have in them and what would the epidural be like? D2 and D4 were worried that some unexpected
medical problem would be discovered before or during the operation and, consequently, they wouldn’t be able to donate.

Some participants, two of which (F4, F7) had already experienced postponements of their transplants, were concerned that something would crop up at the last minute, such as a cold, and the operation would have to be postponed. Some participants also explained that their families were very concerned about them going through a surgical procedure at the same time:

"It was quite an emotional time, leading up to it, with family. They were all very worried, more so than we were I think.... The actual day before, it was very emotional and traumatic with our daughter and son, particularly our daughter because she was terribly upset. That was awful. They were worried about both of us having the operation at the same time. She was very concerned about it, because she had an operation herself a while back, which was cosmetic, and we deemed it unnecessary. We said to her the anaesthetic alone is a risk, so she remembered all of that and here we both were having anaesthetics at the same time (laugh).

I think she was worried how it would affect me and no matter how much you reassure somebody that it won’t, there is a bit of a risk.... But I actually felt very cool and calm about it, right up until the day.”

(D9, wife, 2nd interview).

D4 was particularly concerned that when he got into hospital, nerves would get the better of him and he wouldn’t be able to go through with the transplant, even though he wanted to donate and felt that it was the right thing to do. He was very anxious about this possibility and, although it never actually happened, he did wonder how it would make him, his sister and their family feel if he couldn’t go through with the transplant:

"On Sunday, the day that I went into hospital... I had lots of offers from family wanting to be with me in the morning but I actually wanted someone non-family to come because I thought if I start having worries or doubts then I wanted... well I didn’t know how I was going to feel. I didn’t want to be discussing doubts and my worries with members of my
family because it would be very difficult for them and I probably wouldn’t have got the response that I wanted either (laugh). So my best friend came over and we went out for lunch and then went into the hospital.

The night before I was quite... not panicked... but quite unnerved by it and quite worried about it, but I slept really well, I had a good night’s sleep. But I suppose the thing that really worried me more than anything else was...not being able to go through with it. I was worried that maybe I’d become hysterical and just say no, I’m not going to do it, and the feeling of what a let down that would be. That was probably my biggest anxiety. So when I was on the stretcher, although I was still anxious, it was quite a relief because you’re sort of resigned to it then.

That was my biggest anxiety, but I don’t think that at any point in the whole affair did I ever feel... I always felt that it was the right thing to do, but really I was more concerned about what if I was so worried at the time that I’d have to back out and I just wouldn’t be able to go through with the transplant.... I was thinking, oh where would that leave me... well all of us really. I knew that if that happened I’d just feel awful.” (D4, brother, 2nd interview).

Another significant concern of recipients was that the transplanted kidney might reject or fail. R4 in particular explained that her experience over the past year had compounded this fear:

“I wasn’t worried about the surgery side of it or anything like that. I was much more concerned about the psychological effects if things went wrong for my brother and what he would feel and how I would cope with it. All the time I thought I’ve got to think it may not work and I may be back on dialysis and how am I going to cope with that?

Obviously I really wanted it and got to the point where I was desperate, really desperate for it. I thought it’s my only way forward because the dialysis was just causing more and more problems and I’d had so many episodes of being very poorly.... So it always seemed like it would be too good to be true if the transplant went ahead.

I kept saying to the people at the dialysis unit, I’ll come back and see you, and as a patient not as a visitor. I really wasn’t totally convinced that even if it happened it would be ok, because the previous year there had been so many knocks it was difficult to kind of anticipate something being a success and a change for the better.

I was aware that even a living transplant wasn’t all successful and I also knew that my brother was not a very good match...so I had that at the back of my mind. But it was definitely affected by my experience of so many things on dialysis for the year I’d been on dialysis - things going
wrong and it being such an intense time over a year. I tried to keep positive and focused but there was a nagging in the back of my mind that said...but also to kind of prepare myself for disappointment.

I think other people thought, why are you convinced that it won’t work, but I think it was a self-protection thing in a way. I said to a doctor a while ago it will be a miracle if it happens and she said it isn’t a miracle, it’s not a miracle cure you know. You are going to be on this, that and the other, your life will never be...but I just thought anything’s got to be better than the year I’ve had on dialysis and not be able to walk one hundred metres. I think because I had to adjust to that year, which was, looking back on it, I can’t believe how I coped with it to be honest. But I had got my mind set to cope with that, so then I found it difficult to shift my focus that life could go on and be... better than it’s been for years. It just didn’t seem...you know, I’d seen it in other people but it seemed too good to be true.”

(R4, sister, 2nd interview).

Some families were having transplants around the time that Family 3’s transplant failed and this further compounded their fear of failure or rejection.

When it was time to go to theatre, some participants became emotional but, apart from wishing each other good luck, none had any profound conversations with each other. Most said that the reason for this was because they felt that they had already done enough talking and it was now time to ‘get on with it’. However, some said that there were things that they wanted to say at the time but they chose not to:

“I found I was full up when they came to take him but I didn’t want to say too much because I didn’t want to get upset, for him to see me and I was upset. I thought if I start getting upset it’ll make him... you know. So I said to him are you all right about it, you can back out now you know? No, I’m not backing out now he said... and I just wished him all the best, and he did the same for me.

We tried not to get too emotional about it, it’s difficult really. There were things I wanted to say but (laugh) I thought, oh perhaps not. It was better, some things left unsaid. It was just for me to say all the best, I hope everything goes well and I kissed him goodbye and that was it.
There are certain things that I still get choked about when I’m talking about it. When my husband went down I did feel a bit upset and, even now, when talking about it I get a bit choked.

I wanted to say things like I couldn’t thank him enough for what he was doing and tell him how much I loved him. It was things I wanted to do but I felt it was best left unsaid really, because if I started to get upset about it, which I probably would have done, I didn’t want him going down all upset. So we made it plain and simple really. So I just said all the best, I hope everything goes well. Straight to the point (laugh) rather than get too emotional and sentimental about things. I mean I’ve said it to him since that I can’t thank him enough for what he’s done, but he knows that obviously.”

(R2, wife, 2nd interview).

6.3 The operation and post-operative recovery

The actual operation was uneventful for all participants except D11, who bled profusely during and immediately after surgery. There was a problem with the cross clamp used during the procedure to minimise intra-operative bleeding and he quickly lost 1½ litres of blood just after his kidney was removed. However, the lead transplant surgeon was able to re-clamp the bleeding vessel, control the bleeding and complete the operation as planned. A blood transfusion was then commenced and he was transferred to recovery.

But whilst he was in recovery his wound drains started to fill up with fresh blood and he was therefore quickly taken back into theatre for an exploratory laparotomy:

“I remember being in recovery freezing cold. Then I saw a couple of doctors on my left and I said to them I’m freezing cold and they put some hot blankets on top, which didn’t make much difference. There was a nurse on my right trying to get a line in my hand, for a drip or whatever, but she had a hell of a job trying to find it.

Then the surgeon said, we’ve got a problem, you are still leaking and we need to take you back in again. So I said ok, if I’ve got to go back in, let’s do it.... He said do you want us to tell your wife and I said no, because, knowing her, if she knows there’s a problem she’ll panic straight away....
It turned out that there was a hole in the artery that was slowly leaking. The drain in my side was filling up and they realised it was a bit more serious than they thought, so I had to go back in. So now, instead of having a cut about 8 inches long, I've got a cut about 14-18 inches long.... Anyway they found it, sealed it up and stitched me back up again.

I went from the operating room straight to intensive care on the Monday. I was in there for about a day and I got back to the ward Tuesday dinnertime. I can't remember too much about Tuesday but Wednesday, early hours of the morning, I woke up and I thought that's it, the operation is done and it's over."

(D11, father 2nd interview).

R11 was deeply concerned about his father throughout the immediate post-operative period and, at the time, wondered whether they should have even proceeded with the transplant. It was only when his father's condition started to improve that his fears began to subside.

Despite the seriousness of the situation, D11 felt that he coped with it quite well and felt fairly pragmatic about it, even though some of his family and friends were advising him to consider taking legal action against the hospital. They felt that there was an element of negligence involved and that he could have died. However, he did not want to take legal action as he believed that what happened to him was 'just one of those unfortunate incidents that happens from time to time'.

After the operation, some participants felt reasonably well and were quite surprised by this as they had expected to feel much worse. Conversely, most participants felt tired, sore and uncomfortable for the first few days. Most disliked the monitors and tubes, particularly the urinary catheters, that were
attached to them after the operation. R4, in particular, disliked the monitoring equipment as she found it quite disorientating.

Many participants reported experiencing little or virtually no post-operative pain and were very happy with their pain relief. However, just as many participants complained of experiencing moderate to severe post-operative pain on occasions. Many donors also had problems with their epidurals, which exacerbated their pain:

"The first 4 days I wouldn't want to relive in a hurry. I think that was pretty uncomfortable and you did feel pretty unwell. The pain relief wasn't great for me. I've never had an epidural before, not even when I had the kids. Unfortunately they sited the epidural too high, so I went through all that epidural business and then it didn't stop the pain.

They put me on some morphine but that wasn't brilliant.... I used the PCA a lot because I was in such pain and then of course I became nauseous. And the pump kept playing up and that wouldn't work properly all the time."

(D7, wife, 2nd interview).

Recipients of donors who were experiencing pain were very concerned about their welfare. Some also felt guilty about having put them through a surgical procedure and felt that it was they who should have been suffering and not the donors.

Although most participants started to feel better after a few days, many developed post-operative complications of varying severity. Problems included post-operative nausea and vomiting, urinary tract infections (UTIs) and constipation. No one developed a wound infection but D7 did develop a problem with her wound because a newly qualified staff nurse failed to properly remove her wound suture. The nurse cut the beads off each end of the suture but actually
left the indwelling suture in place because she incorrectly thought that it was dissolvable. Consequently, after discharge, D7 had to be readmitted to hospital as a day case to have the retained suture removed under local anaesthetic.

D11 also developed a problem with his wound after reluctantly mobilising two days after the operation. He got out of bed and sat in the chair with the assistance of two physiotherapists. However, when he attempted to get back into bed he felt that he was not properly supported by the physios and, consequently, he severely strained his wound site. This caused severe pain and, he believed, eventually resulted in the abnormal protrusion of his wound site.

However, the most common complication, experienced by nearly all recipients, was acute graft rejection. Recipients were particularly fearful of this complication and the effects that it may also have on their donor. Many also initially thought that it would ultimately result in their transplant failing completely:

"Day 8 we had a little bit of rejection, which they treated with steroids promptly. That came under control again straight away. It's strange, you prepare yourself for it because they tell you it's going to happen. It's quite common to have an incident or 2.... And when they came back and said you've got a bit of rejection it does hit you a little bit hard because you think that's it, it's all over.

You're prepared for it but then as soon as you're told you start to feel a bit low, but then you think you've got to snap out of it, it's par for the course. Everybody else in the opposite beds have had the same thing and they're all doing fine.... So you tell yourself to buck up basically (laugh) and stop being an idiot.

I think it hit my wife harder than probably myself, which is understandable, she's gone through all that and thinking, oh it could be a complete waste. But no, as soon as I got my head straight, it was only for a couple of hours, I though oh Christ, but you put on a brave face
anyway. It was fine and it wasn’t anything major. As soon as I got treated then it was fine.”
(R7, husband, 2nd interview).

Most families who experienced acute rejection were spoken to by health professionals and reassured that it was a relatively common occurrence, which, in the majority of cases, normally responded well to treatment. With the exception of R3, all episodes of acute rejection did actually resolve with medication. Consequently, family 3’s experiences from this point onwards are different to the other participants and have, therefore, been discussed in a separate section later in this chapter.

R9 also experienced an episode of acute rejection, which resolved with treatment. However, just prior to discharge, his urine output decreased and his creatinine started to rise again. Another episode of acute rejection was initially suspected but, following an abdominal ultrasound scan, a problem with the ureter in his transplanted kidney was discovered, which was impeding the flow of urine from the kidney to the bladder. A temporary stent was therefore inserted and the problem resolved.

Most participants went on to make a good recovery after the transplant, particularly when their drainage tubes and urinary catheters were removed. Their pain generally settled after a few days and their ability to mobilise gradually improved. Most participants were well enough to be discharged from hospital within a few days and many within a week of admission. However, those who experienced serious post-operative complications, such as acute rejection, were
kept in hospital longer for further treatment (up to several weeks, in the case of R3).

6.4 Life after the transplant

Most participants returned home after discharge but some, who lived further south, chose to stay near the hospital in a British Kidney Association 'charity house' for a few days. This made it easier for them to attend the hospital regularly for follow up appointments and blood tests in the first week after discharge than having to travel long distances from home. All who used this house found it beneficial to their recovery.

All participants spent the first few weeks at home recuperating, often with the help and support of family and friends. Most initially took things easy and gradually increased activities, such as walking, as and when they were able to. Many often found this period quite tiring and having the occasional 'early night' was quite common. Many found that their wound sites were still tender and often ached, particularly if they had been strenuous, which frequently made things like bending over and picking things up quite difficult:

"When I came home, for the first few days I didn't do much. I pottered about and so on. I had a real problem getting out of bed for a while. So I pottered around, got quite fat because we were eating a lot of chocolate because it was Christmas. Watched lots of telly. My son came home and looked after me and then [R7] came home on the Wednesday. My son stayed for the whole of that week. That was nice so we had a few days with someone here to help us out.

Then on the Monday we had to go back down to the hospital to start the regular checks and when we came out we decided to go into Cribbs Causeway. We were walking around a bit like Darby and Joan. He was walking this side so he could protect my scar. So 2 weeks to the day there we were stumbling around Cribbs Causeway Christmas shopping."

(D7, wife, 2nd interview).
Although most participants felt that their health and fitness was starting to improve after a few weeks, several developed problems whilst recovering. Some donors and recipients had put weight on after the transplant. Donors generally attributed this to over-eating and inactivity. Recipients also felt that their weight gain was due to these factors but they also believed that it was primarily due to their post-transplant medication, particularly steroids.

R1 had put on 2 1/2 stone in weight in 3 months and this particularly bothered her. She disliked the way she looked (as she had never been large), her clothes didn’t fit properly and she felt uncomfortable and unfit. However, she was now eating more healthily and, since her medical team decreased her dose of steroids, she had started to slowly lose some weight.

Some donors were experiencing problems with their wound sites. Although none had suffered from wound infections, some had wounds that were misshapen and protruding and looked as if they may have herniated. D11’s wound site had not healed properly since the transplant; a problem which he blamed entirely on the incident in hospital when the physiotherapists attempted to move him from chair to bed for the first time:

"I’ve been left with torn muscles on the inside, which I’m still getting trouble with.... I’ve got to see the surgeon tomorrow because I want to know what is going to happen from now on. I’ve got a lump there now, my belly button is out of line... and I’ve gone from a 38 to 41 waist and up to 46 in the night time.

I do get an ache if I’m stood up too long, but not from where the kidney came out, it’s from where I actually tore the muscle. As far as I’m aware if it hadn’t have been for this I’d have been back at work 3 or 4 weeks ago. But the last time I saw a doctor, that was 3 weeks ago, he said be..."
careful what you lift and how you lift or it won’t recover properly. It’s a bit of a bind actually because my grand-daughter, who’s 2½, I would love to pick her up but I can’t just in case something does happen.

I would like to try to get back to work but being an electrician I’m either on my hands and knees or up ladders and if I had to walk up and down steps with a heavy tool bag, I couldn’t see myself doing it. Whether the firm will allow me to do light duties when I go back I don’t know"?
(D11, father 2nd interview).

This situation, and in particular the care that he received from the physiotherapists, had left him feeling so unhappy and annoyed that he was thinking about making an official complaint.

R7 found that he had become more short-tempered since his transplant. However, when he realised that this was becoming a problem he made a concerted effort to control his temper at all times and, since his dose of steroids was been reduced, he found that he was now back to normal and his temper was no longer a problem. R8 felt that she was picking up colds more frequently and it was taking longer to get over them, which she put down to being immunosuppressed.

Some recipients had episodes of acute graft rejection after discharge; a problem which some had also experienced whilst in hospital. Although all episodes resolved with treatment, these recipients had exactly the same fears and concerns as those who had suffered from acute rejection whilst in hospital. For example, they were concerned that acute rejection would ultimately result in the transplant failing and they were worried about the effects that this would have on them and the donors:
"I had a slight rejection early on, which the team said, well you will have rejection. So I had a biopsy and took some methylprednisilone for it and it was fine.

I had come home, but it was still like 3 or 4 weeks after the transplant. I remember feeling quite tired and worried because... when you hear that word rejection, you think that's it. But, as they say, it's very, very common, everyone gets it really and we're treating it, it's nothing to worry about. It was treated quickly so that was fine."

(R8, daughter, 2nd interview).

Several recipients had initially found the post-transplant drug regime quite demanding but all were now getting used to the daily routine. R1, in particular, had been very concerned about the prospect of having to take so many tablets after the transplant but even she had found that it actually wasn't too bad and it was, after all, 'just a small price to pay'.

Life was slowly getting back to normal for most participants after 3 months. Most donors were back in work, although some were currently on reduced hours and/or light duties. Most felt that their health was improving and some had even resumed sporting activities, such as running and tennis. However, some felt that they still lacked stamina and many found that they were still tired on occasions, particularly in the evenings.

The impact on the health of all recipients was profound. All felt that they had more energy than they did before the transplant and most were already doing things that they hadn't been able to do in months or even years, such as gardening, driving and exercise. R9 was helping to build an extension to his house and was actually laying bricks when I arrived to conduct his interview.
Most of those who were working pre-transplant were now back in work, although, like some donors, many were currently working reduced hours or were on light duties. Some recipients were making short-term plans, like going on holidays, which, before the transplant, many had not felt confident about doing, and some had already gone on holidays for the first time in years:

"I was able to walk on the downs and I could feel this energy going through my legs again and that was fantastic. But at first I felt quite tired... it's only now I think, in the last 2 months, that I've felt confident in the ability to do things. I'm getting back to normal now, readjusting to life now compared with then.

I feel clean inside, like I've got rid of all the toxins. I just can't believe the difference it's made. Now I can take an interest in what my kids are doing, whereas before I just didn't have enough energy to do that.

I think it's a miracle, although they do tell me that it's not a miracle cure. But I'm back to sport now. I'm doing yoga and I'm running. I'm thinking of running a 5K soon and maybe even a half marathon eventually with [D4]. I'm able to spend time with the family. It's just nice to be able to sit in the garden and enjoy it without wanting to go straight to bed."

(R4, sister, 2nd interview).

However, the general improvements in the recipients' health and well-being had not only had a positive impact on their lives but also on the lives of their families:

"We've both noticed how it's improved our lifestyle. We get more weekends together now and in the week we do bits and pieces. That's great because Saturday afternoon I used to go to dialysis. We now do things on a Saturday afternoon and you think, well this time before Christmas I'd be on dialysis.

We are now planning some holidays for later in the year. But I feel the benefit already, just quality of life as much as anything else. When I was on dialysis it was alright but it does affect the day-to-day things and working as well. I used to go Tuesday and Thursday afternoons so basically Wednesday and Friday I was knackered because I'd be starting work at say 6 am, finish work at 2. So, yeah, it's nice we have more time together."

(R6, husband, 2nd interview).
6.5 Feelings and concerns about the transplant

All recipients were happy with how their lives and quality of life had improved since the transplant. All were extremely grateful to the donors for donating and some became emotional when discussing this. However, although all had, at some point, expressed their gratitude to the donors, many found it difficult to tell them just how they felt:

"I'm very appreciative and grateful but it's very difficult to say... just saying, oh thanks for that. It's quite, you know, oh thank you for what you are doing is quite meaningless when you put it against what actually she is doing.... I know she knows what I feel but it's quite difficult to put it into words because there are no words really that you can express what you feel about it."

(R8, daughter, 2nd interview).

However, whilst all recipients were appreciative, some were also keen to point out that they would have done the same for the donors if the roles had been reversed.

The improvements in the recipients' quality of life also had a profound effect on the donors. All were delighted with how the recipients now looked and felt and how the transplant had improved the lives of the recipients, their families and, in the case of spousal donors, their life together as a couple. Some donors also became emotional when talking about this.

All of the donors were happy to have donated a kidney and no one regretted this, even those who had experienced problems during or after the operation. Furthermore, nobody viewed their actions as brave or heroic. They all felt that anyone faced with the same set of circumstances would probably do the same:
“People say, I think you’re really brave in donating, but I don’t feel that way at all. I honestly don’t think that what I did was brave or heroic and I’m sure that anybody faced with this situation would do the same really.”

(D1, husband, 2nd interview).

Despite the way in which donors and recipients now felt about the transplant, very few of them had any meaningful discussions about it any longer. Some occasionally discussed how they were doing and some recipients often thanked the donors for donating from time to time, particularly if they’d had a good day, although none felt a need to do so continuously. Some participants also joked about the transplant. For example, donors would say things like ‘look after that kidney, it’s mine’ and recipients would blame any pain around the site of the transplanted kidney on the donor and say ‘that’s your kidney playing up’.

However, most participants now generally had little or no profound discussions about the transplant. The reason for this was because they felt that the subject of renal failure and kidney transplants had consumed much, if not most, of their lives over the last few months or years. Most felt that the subject had simply been exhausted and that it was now time to put it behind them and ‘move on’ with their lives:

“I think you can speak about the physical side about it; the scars and the drugs and my creatinine, which seems to be the topic of conversation a lot. But we don’t actually talk about anything else really. I think that’s because for 10 years we’ve just been through that. We’ve talked about the transplant years ago, about 10 years ago and she said then, I’ll give you my kidney. So we did talk about it on and off over the years and I think you come to a point...when there’s nothing left to say really. I think we’re at that point now, we’ve exhausted that side of it and, as I say, we talk about the practical aspects of it. But we both feel that now is the time to move on.”

(R8, daughter, 2nd interview).
Despite feeling positive about the transplant, most participants, particularly recipients, were concerned about graft rejection and how long the transplanted kidney would last. However, this fear had generally subsided now that they had all reached the 3-month post-transplant stage, as they felt that the risk of acute rejection was now considerably reduced. But some felt that they would only really be able to relax more and start planning for their future when around 6 months had passed. Most recipients, and many donors, were also aware of the need to now look after themselves more by, for example, drinking plenty of fluids and avoiding potential infections like colds and flu.

However, all recipients conceded that the transplant would probably not last forever and, although this fear had now diminished somewhat, it had not disappeared completely. All recipients were beginning to come to terms with this possibility and were dealing with this prospect by utilising very similar coping mechanisms. Most recipients, and many donors, explained that they tried not to worry too much about what might or might not happen to them in the future and would only face up to such problems if and when they arose. Also, all participants felt that they had to make the most of their lives and live it to the fullest while they had the chance to do so:

"The fear of rejection kept recurring every time I had to go up to the hospital for blood tests. I talked to my doctor down here, who I'm very close to, she's seen me through some bad times. The first time I spoke to her after the transplant she said you seem really down and I promptly burst into tears. I said that I was worried about the rejection and would it happen again. We talked about it and she said you have got to stop thinking about that, you've got to concentrate on the future.

But it's on my mind quite a bit from time to time and I do wonder if it will ever happen again or if and when the transplant will fail...you know how long will it last? But you can't really live like that. As the transplant co-
ordinator said to me you have to enjoy yourself and make the most of what you’ve got. So I try not to dwell on it too much.”
(R4, sister, 2nd interview).

6.6 Donor-recipient relationships post transplant

None of the participants felt that the transplant had caused any problems with, or deterioration in, their relationships with one another. Some felt that, since the transplant, their relationships had actually improved and, consequently, they had become closer:

“I said beforehand I think it brought us closer together. It’s made me appreciate him more (laugh). I did before but I think you take each other for granted after a time. And then whenever anything happens like this it hits you…. It’s definitely brought us closer together.

Even [D2] I’ve noticed, where he could jump off the handle about things, he’s sort of calmer with me (laugh). He seems to have altered for the best as well, well both of us really.”
(R2, wife, 2nd interview).

However, most relationships between donors and recipients had not changed in anyway since the transplant. Many felt were there was a potential for the transplant to alter the tenor of the relationship, primarily because of what had been given and received and how grateful recipients now were for the transplant. But these participants did not want their relationship to change because of this and both donors and recipients made a concerted effort to ensure that their relationships with each other remained the same:

“It’s no different actually. We did wonder whether it would change, but no, it feels just as happy and no different. In fact, although we joke about it a lot, I think you don’t want to keep being reminded of it and I just forget about it. It’s just exactly the same really. And I said to him, has it made any difference, and he said no, it’s just the same as before really.”
(D7, wife, 2nd interview).
6.7 Service issues

Participants' experiences of service provision related to three fundamental aspects; the transplant service in general (for example, staff, care, the environment and equipment), the provision of information (verbal and written) and follow up care after discharge from hospital.

6.7.1 Service in general

Although areas of concern were discussed, all participants were generally very happy with the transplant service. Some families were so happy with the care they received at the centre that they now wanted to 'give something back'. For example, several families had volunteered to attend live donor information evenings for the transplant unit whilst others were planning to organise fund raising events to raise money for equipment and furniture for the hospital and medical staff. Health professionals in particular were praised for their skills, help and support, especially the consultants, the transplant surgeon and the live transplant co-ordinator:

"The care was very good. I really like the surgeon and the transplant co-ordinator. My brother really liked the staff and found their support excellent as well. One day when I was quite down about the rejection thing the nurses on the ward told the transplant co-ordinators and one of them came up and talked to me about it for half an hour. It made such a huge difference. She explained to me that rejection can be quite common and usually resolves with treatment. That was great, I felt much better after that...she was really good."

(R4, sister, 2nd interview).

Throughout their stay in hospital, donors and recipients were generally kept in the same bed areas as each other, which everyone found to be mutually beneficial and supportive. Many participants also found being in the same environment as
other transplant patients, whose experiences they could often draw on, helpful and enlightening:

“It was definitely nice being opposite and being able to keep track of each other. Because we have been through an awful lot, we were there for each other and I would be able to see what was going on with him. I just wanted to keep track of him and I was worried that if we were separated that it would have slowed both of us up.”

(R6, wife, 2nd interview).

However, some participants were unhappy with certain aspects of the general service. For example, some participants were disappointed with the appearance and layout of the transplant ward, as they felt it looked run down and afforded them little privacy. Some families also complained about the post-operative analgesia devices that were used for administrating PCAs and epidurals.

Several participants experienced recurrent technical problems with their analgesia devices, which occasionally resulted in them receiving little or none of their prescribed PCA or epidural for varying periods, occasionally at night. Generally only the pain nurse (who did not work nights) was able to resolve these problems. Consequently, although these participants were given alternative forms of analgesia if required, they felt that they experienced unnecessary post-operative pain.

Family 6 felt that the general transplant ward was occasionally short staffed, although mainly in comparison to the high dependency unit (HDU). Some donors felt that live transplant co-ordinator’s time was very ‘precious’ and that they, and perhaps other patients, would have liked to have seen her more whilst they were
in hospital. However, they were aware that she was very busy and, at the time, was employed as the only live transplant co-ordinator on a part time basis.

Donor 8 (an ex-army nurse) did not complain about nursing care in general but she did feel that, on occasions, some nurses concentrated more on the technical aspects of care than on basic nursing care. Donor 11, however, was extremely disappointed with the care he received from the physiotherapists whilst in hospital. He blamed them entirely for his wound problems and felt that their actions bordered on negligence. In fact, he was so ‘disgusted with their treatment’ that he was now contemplating legal action.

Some participants also complained about the noise levels on the transplant ward at night, which they felt prevented them from sleeping:

"The only thing that we found very difficult was the noise at night, (sigh) it was terrible.... Noise from other patients and the noise the staff made. They didn't respect the fact that it was night at all. There was all banging and lights on and off, shouting, you know. I couldn't sleep. That was the worst thing about it, I couldn't sleep.

It was like that every night. Really I think it is something that needs to be addressed. I know [R8] was nearly besides herself with not being able to sleep. I hated it, it was the worst thing about it."

(D8, mother, 2nd interview).

Family 7 were also unhappy that their initial transplant date was postponed because of a problem with their ULTRA application. The hospital blamed this delay on a postal strike but, nonetheless, the family felt that the ULTRA application process could have been handled differently and the whole procedure was now in need of review:

"I suppose it wasn't a very good experience because we got cancelled because of the ULTRA forms. It depends which story you hear but I think
there was a combination of the postal strike and they were a bit late going in. So I think there is probably something they could do about refining the process a bit.”

(D7, wife, 2nd interview).

6.7.2 Information

Most participants felt that, in retrospect, the provision of information from the transplant service had been good. Participants generally felt well informed about the transplant and what to expect subsequently. Many found most health professionals, particularly the transplant coordinator, informative and willing to answer any questions that they had. For most families, however, the major source of information came from the live donor evening, which everyone who attended found helpful.

However many participants felt that certain areas of information provision needed to improve. For example, some participants felt that the provision of pre-operative information should have been provided to them earlier than the night before the operation. Many felt that they needed more time to understand such pertinent information and to consider treatment options such as whether or not to have an epidural:

"I was well informed apart from the immediate post-op side of things, about the pipes and tubes and so on. I wasn't really sure what they were going to do. It was only when it got explained the night before by the anaesthetist.

His explanation was good but it would have been quite nice to have known about all these tubes and things beforehand. Not that it would have made any difference, but it would have been nice, instead of suddenly being told about 6 or 8 hours before you are going down.

It was a shame. We'd been to all the talks about it and the actual operation but not about the actual bit beforehand, you know, perhaps that
was a bit skipped over. I think they should go through that stuff with you beforehand, not when you actually get there."
(D1, husband, 2nd interview).

Family 4 felt that, although the live donor evening they attended was informative and balanced, in future it may be useful to invite along families who have experienced complications after the transplant. They felt that this may help to present a more balanced picture to potential families, although they acknowledged that such an approach may present problems:

"The live donor evening was really good and very informative and helpful. But they only really have couples there where everything has been ok.... It's quite common to have problems after the transplant but they never had families like that when we went. They did touch on the downsides but perhaps in future they could have families there who did have some problems after the transplant just so people know that things can and sometimes do go wrong after the transplant.

Perhaps they could tell you more about that sort of stuff or invite a couple along who have had some problems. But maybe at that time it's not really a good idea. Perhaps if you know too much beforehand it might put you off. I don't know really."
(R4, sister, 2nd interview).

Some participants felt that discharge information, particularly for donors, also needed to improve. They felt that information such as what to expect and what you should and should not do afterwards (for example, how long should you refrain from certain activities) was unclear and non-specific. They suggested that this area could be improved through the provision of more detailed verbal information on discharge from hospital and supported by a discharge information leaflet or booklet, suitable for donors and recipients.
6.7.3 Follow up care

All recipients were happy with their follow up care after discharge from hospital and felt able to phone the hospital for help or advice at any time if they wished. Recipients were initially seen several times a week at the transplant centre but this had now been reduced to several times a month for most. Most recipients living in the South of England had now also had their follow up care handed back to their local hospital. This made travelling to and from appointments far less demanding and helped to reassure recipients that their health must be improving.

Some recipients found it disconcerting waiting for their blood results after follow up appointments. For example, if their blood results were abnormal (e.g., raised creatinine level), hospital staff would phone them later that day, around 3-4pm, and ask them to return to the hospital, that day or soon after, for further tests. Several, particularly those who had already experienced an episode of graft rejection, always felt nervous around this time of day after a follow up appointment and could only relax properly if and when the phone did not ring. They felt that this restricted their ability to plan ahead and reduced their sense of control of their lives. However, as the frequency of follow-ups decreased, they felt that they were beginning to regain control.

Whilst some donors were happy with their follow up care most, regardless of their relationship to the respective recipient, were not. D6 felt that her first follow up appointment, at 3 months, was too long after the transplant and by this time she had already gone back to work.
However, the most common complaint from donors was that follow up care for them was totally insufficient. Many felt neglected by the transplant team, particularly in comparison to the recipients, and were concerned about potential problems that might go undetected:

"It's virtually nil, really. I know the transplant co-ordinator is trying to get more attention going. I came out in early July and was seen at the end of August and apart from that there's nothing now. It will be a year now before I see anybody again. Although I'm alright in myself, I think that's a bit disconcerting. I know you can go and ask and get it sorted out but I do find that a bit strange. With donors it's almost thanks very much and good-bye.

I spoke with the transplant co-ordinator about this and she just sent a letter around recently to say that she's trying to get together a kind of club of donors who can have a talk about it. I don't know what we expect really, I mean what do we want a badge or something, I don't know (laugh)?

I did find it strange being sent home and as far as they were concerned that was it for me, for 7 weeks.... Because my Creatinine level was quite high when I was in hospital and they were doing tests. And that was just pooh-poohed, oh it'll be alright, it'll go down. But it was concerning me, you know, shouldn't somebody be checking this once every 3 months or something like that to see if it does come down. They said oh you can go to your GP and get it checked if you want to. So I suppose they have sort of followed it up but it is just brushed aside I felt, just sort of dismissed. You'll be alright kind of style.

I just sort of said to the transplant co-ordinator that I thought it was a bit odd that there didn't seem to be any sort of follow up at all. I don't really mean medical checks... I'm easy going but I can imagine that some people find it quite traumatic afterwards. They tell you in the talks it can make you suicidal and all sorts but nobody bothers to check whether it has or not. I find that rather odd (laugh), considering my wife comes 3 times a week and is checked left right and centre."

(D1, husband, 2nd interview).
6.8 Family 3’s experiences

Family 3’s post transplant experiences were significantly different to the other participants because of their graft failure. Their experiences from this stage onwards have, therefore, been coded as follows:

- The impact of rejection
- Treatment issues and options
- Coming to terms with rejection
- Service issues

6.8.1 The impact of rejection

R3’s post-operative recovery was initially uneventful until she developed an ileus 48 hours post transplant, causing profuse abdominal distension and severe discomfort. Subsequently, her renal function began to deteriorate (although it is unclear if the two episodes were related), resulting in reduced urine output and fluid overload with an associated weight gain of over 15Kg, thus prompting immediate medical investigations:

"I was really ill the weekend after the transplant and by the Tuesday it was all disaster really. This was over the space of 5 days. At first they thought I had a clot in the vein, in the graft. And I went and had an ultrasound and whereas the first ultrasound had shown that I had very good flow and everything was fine, the second one there was hardly anything there. Which was very distressing for me, because as a radiographer, I knew what to look for and I could tell straight away. Then the radiologist went off and got somebody else and they came and looked at it and they all went off in a corner and I knew then really that I was in big trouble."

(R3, wife 2nd interview).

Aggressive treatment was immediately initiated in the hope of saving the transplanted kidney. This included large doses of heparin and immunosuppressant therapy, all of which made her feel unwell and caused severe nausea and vomiting. Despite this treatment, her renal function did not improve
and it was therefore decided that a renal biopsy was necessary to establish the viability of the graft:

"I had a biopsy... 7 or 8 days after it all went wrong and then it took 2 days for the results to come back. But in all that time, in my heart of hearts, I knew it was no good. None of the drugs made any difference I thought it's not going to be any good really. So although when it came to the crunch and they said it's not going to work it was awful, by that time I'd got there by myself actually...."

(R3, wife, 2nd interview).

The biopsy established that the transplanted kidney had catastrophically rejected and was therefore no longer viable. Several days later her transplanted kidney, along with one of her own polycystic kidneys, had to be surgically removed under a general anaesthetic, so that she could eventually receive CAPD. The emotional effects of these events on R3 were profound:

"When I was in hospital, it was dreadful. It was like a bereavement almost.... Part of that I think is to do with the fact that you are in an alien environment and no matter how nice people are there is no privacy.... It's hard coming to terms with something like that in a ward full of other patients, a lot of whom have had successful transplants. And there was me with everybody talking about me in the corridor and I could hear it, and that was horrid. That was really bad. It's a huge emotional thing, well what's going to happen to me, you know, it's not going to work any longer."

(R3, wife 2nd interview).

R3 remained in hospital for over a month because of her problems - the longest of any participant in the study. However, the impact of the rejection was significant and affected her physically, psychologically and socially. She became anaemic, experienced considerable weight loss and felt generally unwell and lethargic. However, the most significant effects were emotional, resulting in anxiety and severe depression, particularly around Christmas time (shortly after returning home from hospital). She also felt that her experience was so profound that it had changed her as a person:
"Now if I have a little set back, whereas once upon a time I would have thought bugger it, it will be fine, now every little thing worries me tremendously. I certainly found in hospital that before the operation I was calm, composed, really not worried. But in the course of the month that I was in hospital I sort of changed from that kind of person. It was an awful emotional strain and that took a lot of getting over....

So it's not just a physical thing it's an emotional thing as well. You know I've had to deal with being the illest I've ever been in my life, physically, and also very emotionally stressed as well."  
(R3, wife, 2nd interview).

However, whilst R3 admitted to feeling very depressed, the true extent of her depression was only revealed by D3, who explained that she had, in fact, been so depressed around that time that she was suicidal. However, he felt this was due to a number of factors and not solely due to the rejection:

"Around Christmas time all she really wanted to do was end it all. She was talking about jumping off the weir down here, but that's when she lost it completely but she hasn't been like that since. I wasn't aware... it's a classic isn't it, she was hiding that from me because she didn't want me to know, because she knows if I knew I would do something about it and my way of coping and dealing with that probably wouldn't be what she would want. And secondly I think she felt well (sigh)... I've never really dwelt on it because I've never really been there, but if somebody gives you a kidney and goes through that and it fails then the last thing you want to do is, and I suppose there is some angst, guilt, to then go and offload on that other person as well. All those other things, it probably doesn't seem fair."

(D3, husband, 2nd interview).

When D3 realised that his wife was suicidal, he immediately contacted her GP who made an urgent house visit shortly afterwards. Following a medical examination, her GP then contacted the transplant centre for advice and subsequently prescribed a course of sleeping tablets and anti-depressants. D3 admitted that this was the lowest point of his wife's depression and since that day she has improved somewhat.
Whilst she remains depressed, she has never been as depressed since and, according to D3, was no longer suicidal. However, he felt that this experience had affected her as a person. He explained that she had experienced a cot death several years previous and this, together with her rejection experience, had now compounded her belief that she must be an ‘unlucky person’.

Consequently her experience and her depression have also had an effect on their relationship. D3 felt that she put on an act with other people, such as friends and family, but was only ever depressed with him and this had put a strain on their relationship. She also admitted that the experience had affected their relationship:

“It has changed I suppose, in a way. Probably temporarily, I suspect, in that because I've been so unwell I've been very dependent on him, which I'm aware of very much. But I've relied on him much more, I think, than I would have done if it had been successful. If it had been successful I'd be back at work by now. I find that very hard because I don't like being dependent and it's altered the tenor of our relationship as far as I'm concerned, because he has to do things that I used to do and I hate that.

But the other side of it is that it's probably deepened it in a way, because we've been through it together and he knows better than anybody what it's been like. And of course it's been a huge loss for him, because he didn't just do it for me he did it for us really and I think I feel that more than he does. He says that he would do it all again tomorrow and he's got no regrets about it at all. I'm sure if the roles were reversed I would feel the same and I would feel devastated for him, and I think he does for me but he's a very practical person.

So it has changed with both of us being ill your relationship alters .... I think we'll be fine ultimately, but it is difficult and because I don't feel well sometimes I get tired and snappy and think oh why can't he put the bins out without me asking? And then I think oh this is awful, the poor thing, how inconsiderate. So it is difficult.”

(R3, wife, 2nd interview).

6.8.2 Treatment issues and options

Following her graft failure, R3 had to receive HD for approximately 3 months, which she neither wanted nor anticipated. She also detested it and found it
exhausting and depressing, particularly because she experienced a number of problems during her treatment. This included recurrent infections, post-dialysis hypotension, headaches and nausea and vomiting.

Her dislike of HD was also compounded by the fact that every time she went for treatment at the hospital she would meet other people receiving HD who also had ‘horror stories’ to tell about dialysis, failing transplants or the amount of time they had spent waiting for a kidney transplant. At that stage she could barely deal with her own situation and found it difficult to have to listen to other people’s problems.

However, she was now receiving CAPD and, whilst she did not want to receive any form of dialysis, found it much easier and more bearable than HD:

“Having CAPD, I feel a lot better because I’m in charge of my own treatment. I can see that it’s fairly sustainable in the medium to long term, if I have to do it. I suppose that, in a way, it has made me more reconciled to my situation at the moment, but in another way it’s made me think whatever I do and whatever happens to me I’ll never ever be normal again. I’ll never be free of worry and I’ll never be free of pills or dialysis or something, whatever happens to me. But then I guess that’s what happens to lots of people, so you just have to get on with it don’t you?

It’s much better on CAPD though. It’s not what I envisaged would happen to me, but then it’s either that or kicking the bucket and I don’t quite want to do that yet.”

(R3, wife, 2nd interview).

D3 felt that his wife’s loathing of dialysis, and HD in particular, was due to the fact that she had never seriously considered the prospect of the transplant rejecting. Furthermore, apart from being problematic, the dialysis was also a constant reminder to her of the failure and of her illness:
"I think my wife’s mindset is more detailed than mine and her outcome was not having to do anything; no haemo, no CAPD, just successful and when it wasn’t she began... I mean going to dialysis, apart from the fact that it made her feel shit, was a constant reinforcement that she was sick and she didn’t want that because she’s normally on the other side (laugh). The CAPD she doesn’t have to go with other sick people...but all the paraphernalia upstairs reminds her obviously that she does need that treatment."

(D3, husband, 2nd interview).

Despite her recent experience, R3 still felt that a kidney transplant was her best long-term treatment option. Whilst she was initially very reluctant to even think about the possibility of ever having another kidney transplant she had, since her general health had started to improve, recently started to reconsider this prospect.

Her consultant had told her that she had a good ‘matchability score’, meaning that a suitable cadaveric kidney may be found sooner rather than later. He had also reassured her that if she has another transplant, a comprehensive anti-rejection treatment plan would be immediately initiated to reduce the likelihood of another irreversible episode of graft rejection. Whilst she still had mixed feelings about another possible transplant, this information had reassured her somewhat and confirmed to her that a transplant was probably still the best option for her:

"I’ve discussed it with my doctor and I think whatever happens, whenever it happens, because of what’s gone on in the past, will be part of it and I can’t help that. You can’t expunge the whole thing from your memory but on the other hand I could have a transplant next week and it will all still be very fresh in my memory and I could have a transplant in 2 years time and it will still all be very fresh in my memory. Whatever I do it’s there, it’s part of me, it’s part of what happened and I can’t do anything about that. All I can do is say to myself these are 2 separate events and forwarned is forearmed.

But other people have rejected kidneys, I’m not alone. I may be the only one who’s done it to their husband’s kidney, so far, but there’ll be another one sooner or later. And other people have had this experience
and they've gone on and had other transplants and been fine so that's what I have to think about. That's my aim if you like. The reason I try to be positive about the dialysis and getting well again is because the fitter I am the better it will be.

If my bleeper went off now I'd go... and the difference would be, at the moment, the thought of having another operation, any operation not just a kidney transplant, I wouldn't relish it but I would do it because my perception is still that that's the best form of treatment for me. I think if my outcome had been more positive, I probably would view it differently.... Having had the operation and everything I can see why people who do well on dialysis choose not to go for a transplant. I would never have countenanced that before my experience, and I still wouldn't now really, for myself because I'm still very young in medical terms and I'd be a long time on dialysis even to see my son grow up, who's 13. So I want to make the most of my opportunities and my treatment so I'm firmly convinced still that the best treatment option for me is a successful transplant. But I could see why someone 15 years older than me might feel differently.

I think the further I get away from last autumn the more receptive I'll be towards having a transplant and the better I'll be able to cope with it when it happens. Although I'm on the list I wouldn't be tremendously excited if it happened now. I'd be more apprehensive than excited. But I think 6 months down the line I'll feel a lot differently.”

(R3, wife, 2nd interview).

6.8.3 Coming to terms with rejection

R3 was still struggling to come to terms with recent events. Whilst she was in hospital she had invested all her energy into just getting home. But when she eventually achieved this short-term goal, although she was happy not to be in hospital, she became very depressed. Although she feels that she has ‘moved on’ from this phase and feels better, she is still depressed about the unanticipated situation.

When she first came home from hospital she, like her husband, initially found it difficult to sleep. Most nights were spent in bed sleeplessly reliving previous events, thinking about what had happened and wondering ‘why me”? She found
that this perpetual cycle was making her more depressed and preventing her from ‘moving on’. However, she has now started to put her experience into some sort of perspective in order to ‘get on with her life’:

“...It’s not what either myself or my husband wanted, or expected, or were led to believe would happen. So it’s a lot to come to terms with, it’s a lot to rationalise and deal with and lots of new things I’ve had to learn that I didn’t think I’d have to learn.... In the grand scale of things, I’m still here, I’m still alive and getting better and I have to make a life for myself. It’s a different life from the one I thought I was going to have but I’ve still got the chance of another transplant.

The other thing is should they have given me something stronger before the operation, but of course that’s hindsight. Nobody knew it was going to happen, it’s just a series of what ifs and you can’t spend your life thinking about that. You have to get on with it. Because it’s going to happen, statistically, sooner or later, someone is going to cop it.... It’s my shitty luck that it happened to me, it’s just one of those things. Sometimes I say to my husband why did this have to happen, it shouldn’t have been like this, this wasn’t what we wanted? But it’s what we’ve got he says. You can only work with what you’ve got.”

(R3, wife, 2nd interview).

R3 felt that she had not yet really developed a definitive coping mechanism for dealing with the graft failure. However, she now dealt with the situation by taking things ‘one day at a time’ and felt that each new day moves her further away from ‘that awful experience’. Her mood had lifted somewhat recently since she finished HD and started CAPD because she felt better physically, she hated HD and felt that CAPD offered her more control over her life and was nicer than HD. She hoped that this gradual physical improvement would continue and believed that as it improves, so would her life in general and this, along with the prospect of a future kidney transplant, was currently a source of optimism for her.
For family 3, and R3 in particular, the main way they have dealt with their situation has been to support each other through the process. R3 admits that her husband has been extremely supportive of her. However, D3 found it extremely difficult to constantly support his wife over the last few months. He felt that they had very different coping styles and, consequently, he doesn’t know how best to support her:

“Whatever happens has happened and you’ve got to make the most of it.... It wasn’t the outcome that we had anticipated by any stretch of the imagination, but we knew that it was an outcome. I can remember them saying and how will you feel if it doesn’t work? We’ll cross that bridge when we get to it was the answer I suppose. Well we got there and we’ve got to get through it now.

But the hardest part for me I suppose, apart from her being depressed all the time and in pain, has been not knowing how best to support [R3]. I try to jolly her along but I don’t know if that’s right.... Everyone says to her you have a good old weep, it’s good for you. But is it really good for you? I don’t know? Ok get it out of your system but let’s move on from there.

She will sit and worry about it, but worrying about it isn’t going to help. But that’s the way she deals with it and I’m different in my character. I’m too practical, it’s not that I’ve been unsympathetic it’s just I (sigh)... I have this feeling that once you let yourself be a victim... or it hasn’t worked therefore nothing else is going to work then it becomes a self fulfilling prophecy.

I don’t believe it’s good for her to dwell there, so I keep being positive and try to rationalise it with her. I can only be supportive and I think I probably have been very supportive. I am a liberal but all this poor you bit, whereas there is a place for it, I don’t think me reinforcing that message at home is a healthy thing for me to do. I want to keep her moving on. Out of all of this that has been umpteen times harder to cope with than being told that the kidney has failed.”

(D3, husband, 2nd interview).

However, both now felt that she was improving physically and emotionally and, since commencing CAPD, had started to regain some control back in her life.

Although he hardly talked about his own physical condition, and said he felt a bit of a fraud in comparison to his wife, D3 had also experienced some physical
problems since the operation. He regularly experienced pain and discomfort around his ribs (which he broke several years previously playing sport) and the wound site. His wound also protruded abnormally, was slightly numb and had reduced his movements somewhat. He found it uncomfortable to sit, stand or walk for long periods and regularly had to take analgesia such as paracetamol and even tramadol. He was, however, being regularly followed up for these problems, which he was happy with, although no further treatment had yet been suggested.

6.8.4 Service issues

Despite the graft failure, family 3 were generally very happy with service provision from the transplant team and focused on two main aspects in particular; service issues in general (e.g., care and support) and the provision of information.

6.8.5 General service issues

Family 3 were generally very happy with their treatment, care and support. They did not blame the transplant team in any way for the kidney rejecting and felt that everything that could have been done for them, medically, was done. They felt that the medical and surgical teams communicated well with each other and with their local hospital.

Whilst the staff in the hospital were generally very caring and supportive, family 3 felt that they also recognised that R3 and D3 were mutually supportive of each other and, in particular, R3 was dependent on her husband for support. Consequently, they both felt that D3’s discharge was delayed somewhat, even
though he did have recurrent UTIs, to allow him to stay in hospital and support his wife. Even after discharge from hospital, D3 was allowed to stay in the British Kidney Association house close to the hospital so that he would be near by and they both valued this greatly:

"Everybody at the hospital was absolutely wonderful. The staff on the ward were tremendous, very caring, nothing was too much trouble.... The co-ordinators, all the doctors were really superb and I think they were almost as upset as we were to be honest. I didn’t have any sense of it of me just being a person who’d gone wrong. I really felt that they all cared about us both me as individuals and felt for us and really tried their hardest.

I think they did everything that they could and I’ve looked back and wondered well maybe they should have done that or this but in reality I don’t think that there was anything more that they could have done.

Knowing that it was all a waste of time really. But on the other hand if they hadn’t tried I’d be sitting here now saying they never did anything, you know, they just took it out straight away. So I appreciate the reasons behind it and I don’t think anything could have been done differently to be honest.”

(R3, wife, 2nd interview).

However, whilst most health professionals were very supportive and empathetic, R3 felt that some did not quite know how to support her emotionally. She found the some members of staff were standoffish and utilised a ‘false breeziness’ at times around her. However, she felt that this was due to uncertainty and ‘self-protection’. She also felt that when her consultants broke the news to them that the transplant had failed and therefore had to be removed they also didn’t quite know how to handle the situation, although they did their best in the difficult circumstances.
However, R3 felt that the emotional support provided to her by the transplant team after discharge from hospital, particularly when she was suicidal, was totally inadequate and unacceptable:

“When I was really depressed just before Christmas I could have done with somebody just to kind of off-load on really, because there is a limit to how much you can dump on your partner I think. I found that quite difficult.... There's a renal counsellor at the centre and the dialysis centre rang her up and said that I was not very well and we think she needs a bit of support and she just left a message on my phone saying ring me up if you want to talk to me. And I thought no that's not how it works. Perhaps it's just me, but I can't make an appointment to go and be counselled, I just wanted somebody to sit and listen really. I didn't want to sit on the end of a phone talking to somebody 50 miles away. So I never did take her up on it, I thought by the time I get there whatever it is I wanted to say will have gone, so I never bothered really. I just went on dumping on my husband.”

(R3, wife, 2nd interview).

However, she did not elaborate on what she wanted from such a service, how it should operate or how such a service could be improved for future patients. She just felt that it was an aspect of the service that ‘needed to be looked at’.

6.8.6 Information

D3 felt that the provision of information by the transplant team, before and after the transplant, had been good. He also felt that they provided sufficient opportunities to ask any questions and/or to seek further information if required. Both he and his wife felt that when the transplant rejected, the transplant team explained the situation extremely well to them and always kept them well informed about the situation:

“I think they probably overcooked the explanations but I suspect that they may have been concerned that somehow they had been at fault, because nowadays it’s got to be someone’s fault. So they went out of their way to talk us through that, I think for 2 purposes; that they wanted us to know precisely what they were doing about it and what they were learning. I
just wanted to know why it hadn’t worked so I could understand it, not so that I could weigh up my odds of suing them.

They were very honest and I think that was in the back of their minds, but I’m not like that anyway.... They had to go through the business of it wasn’t a human fault, which I couldn’t stop them doing.... I said look I’m not remotely interested in that, what I’m interested in now is, is there anything that can be learned that will help others and is what we’ve been through going to help or hinder her chance of getting another transplant? That’s really all I wanted to know.

But if we were going to have it done again, which we may well have to do with a bit of luck, I wouldn’t want to be anywhere else, because I felt safe and looked after.”

(D3, husband, 2nd interview).

However, R3 now had reservations about the balance of information presented during the live donor evening. She admits that potential problems were discussed during the evening but felt that they were almost ‘skimmed over’. She also felt, as some other participants had, that families who attended the evening and had apparently experienced little or no post-operative complications, were helping to portray an unbalanced picture of reality, given the frequency of problems such as acute rejection.

Consequently, she now speculated as to whether she could have been better prepared for the rejection by the transplant team if more attention had been paid to potential serious complications such as rejection, although she admitted that her views were now heavily biased by her experience:

“I’m not sure it would have made any difference to be honest, because we did know there were risks attached and did know there was the possibility of failure. But I do think, and this is because my view is skewed by what’s happened, that when we went to a live transplant evening the whole question of things going wrong was just skimmed over and I can understand why that is because it’s a huge thing for the donor and the recipient.
But although we knew about things like post-operative complications like clots and things like that, I never really entertained the thought that I would have such a catastrophic rejection and that it wouldn't work. I knew that people with transplanted kidneys have rejection episodes but the whole tenor of it was, we can cope with these with strong drugs. But it never got stronger than that, so when it did happen we were entirely unprepared.... I don't think it's complacency I just think that I might have been better able to cope, or I might have not been so devastated if... that had been introduced in a kind of fairly serious way, rather than just everyone has a couple of blips.

And that's why I suppose I now see transplants in a different light. I hadn't realised how many people had... quite a difficult time really. And I can see that it's not the panacea that maybe everybody thinks it is. Not that its put out to be by doctors but as a lay person where kidney transplants are concerned you think well I'll have to take some pills for the rest of my life but I'll be fine.

But I think that not enough was said about the possible downsides. But it's a bit like being told you may reject, you think oh it won't be me, it'll be somebody else. But I do think that they need to be more up-front beforehand."

(R3, wife, 2nd interview).

6.9 Conclusion

In this chapter, data from interviews conducted 3 months post transplant were presented. In the next chapter, data from the final phase of interviews, at 10 months post-transplant, are presented.
CHAPTER SEVEN: The interviews: 10 months post-transplant

7.1 Introduction

In this chapter, data from the final interviews, conducted at 10 months post-transplant, are presented. All interviews were conducted individually, in private, at the participant's homes, except family 9, who were interviewed, at their request, in a private room at the transplant centre following an out-patient's appointment.

Themes arising from participants' accounts have been categorised as:

- Getting back to normal
- Post-transplant complications
- The impact of the transplant on donors and recipients
- Concerns for the future
- Service issues

Family 3 were also interviewed at 10 months post-transplant but, again, their experiences are discussed separately because of the graft failure. Their post-transplant experiences have been categorised as:

- Getting back to normal
- Treatment issues
- Service issues

At the end of the final interviews all respondents also discussed how they had found participating in a series of research interviews. Themes arising from these accounts have been categorised as:

- The interview experience
7.2 Getting back to normal

Whilst many participants had experienced some problems post transplant, all now generally felt fit and well and most believed that they were either ‘back to normal’ or very nearly so. Most donors were back in work and had resumed their pre-transplant working hours and duties.

Donors felt that their health and fitness levels were now generally comparable to pre-transplant levels. The occasional feelings of tiredness had passed, although some felt that they could sometimes ‘feel it’ if they over-did things. Most donors had also fully resumed hobbies and sporting activities with little to no problems:

“*My health has improved since I last saw you. I’ve started a new job and feel fine. It’s quite demanding, long hours and lots of travelling but I feel fit enough to be doing that. I’ve had a couple of holidays over the summer, both of which involved physical activities, mountaineering and stuff. I think I’m now back to a similar level of fitness as I was before the operation.*

*I went to Switzerland in the end of August and I didn’t know quite how I would fare, climbing quite high. And I found that I had no problem at all. There’s no pain associated with the wound. I’ve run 2 half marathons now, one in March and one two weeks ago. The last one I could feel the scar aching, but it’s not unpleasant and it still makes me feel pretty good, to know I did it.*”

(D4, brother, final interview).

The improvements in all recipients’ lives were profound, for them and their families. Their general health and stamina had improved since the transplant and continued to improve. All had noticed an improvement in their general health and well being, and this was especially so in those who had been on dialysis pre-transplant:

“*Oh it’s unbelievable... I haven’t felt so well in about 5 years. I realise now how ridiculously unwell I’d got before I actually started on dialysis. I’d got to a stage where I was in bed sleeping, and I didn’t have the energy to even want to go to the hospital to get treatment.*
When I think about it now I know I was dying slowly, but at the time when you are in that situation you don’t. You just think, oh I’m tired, I’ll sleep. I think that’s what is frightening and horrible about kidney failure is that it’s insidious. You get lulled into this, I’m tired I don’t want to do this, I want to sleep. I mean I’d get up go around the house for a couple of hours and then go back to bed and then sleep all night and I accepted that.

With what I do now, that seems absolutely awful, it really does. I think mine was actually a severe case. It’s unimaginable, it really is. It’s quite hard... to have thought that I might have carried on like that and now I’ve got this incredibly, amazing thing. You can’t express how amazing it is and I want to ring my brother everyday and thank him.

I’m getting back into a normal living now. The whole regime of being on dialysis, your life revolves around hospitals. That’s changed now and I’m back to the person I was, the independent self, that I was before...." (R4, sister, final interview).

All recipients had fully resumed activities such as driving, gardening, exercise and daily living activities. Some had joined gyms and were able to do more activities than they had been able to in years, such as walking, going to concerts and generally enjoying life. Most felt that they were already able to do most of the things that they could do before they developed kidney failure. However, some recipients felt that their recovery had, at times, been slower than anticipated, although they admitted that, with hindsight, their expectations of recovery had probably been unrealistically high.

Recipients who were working pre-transplant were now back in work and had resumed their pre-transplant working hours and duties. Many had been on holidays and some had gone abroad for the first time in years. Many were also making medium to long term plans for the future, which they hadn’t previously felt confident about doing:
"Everything has been absolutely fine. It gets better. I went back to work in February and was back full time in early March. But comparing now with back then... I think you can’t really describe the difference. How you feel, for me you don’t immediately feel it at all. It’s just when you’re doing little things I think, oh I couldn’t do this before. This summer I swam in the sea for the first time in probably 15 years. I would never have done that before. I was too cold, I was too ill, I was scared of getting something. And it was fantastic and those sorts of things hit home the most. So I would say, yes it’s completely different from before the transplant.

I really lived for the day before the transplant because I didn’t know if I’d wake up the next day. But now actually I can make plans, future plans. I’m going to get married next year and that has all happened since the transplant. I felt that I couldn’t do that before the transplant.”

(R8, daughter, final interview).

All participants felt that their family life had improved significantly since the transplant and those involved in spousal donation also felt that their life together as a couple had improved. All felt that they were now able to do more as a family and/or as a couple, since the transplant, such as socialising and just ‘enjoying life and living again’.

7.3 Post transplant complications

Whilst the lives of participants were generally returning to normal, most had experienced some problems, of varying severity, since the transplant. R1 was still experiencing problems with her weight, which she blamed on steroids, and this continued to irritate her. Some participants (donors and recipients) had suffered from recurrent UTIs, which required repeated antibiotic therapy. R11 had experienced erection problems because of his anti-hypertensive medication, although he had now been offered appropriate medication if he so required.
Some recipients had experienced mild episodes of acute rejection between their 3 and 10 month interviews. These incidents had primarily occurred after their anti-rejection drug regime had been altered. However, all episodes had promptly responded to the appropriate treatment and did not reoccur.

Most donors had suffered problems with their wounds or wound sites. D2’s wound site was misshapen and appeared to have herniated and, at the time of the interview, he was awaiting a surgical review. A small part of D4’s internal suture had protruded through his wound and he had to return to hospital to have this removed under local anaesthetic.

D11’s wound was also misshapen, a problem he blamed on the physiotherapists, and he had to have an operation, 8 months post-transplant, to try to rectify the problem. A supportive mesh was inserted into his abdomen to try to support his wound site. Consequently, he now had reduced sensation around the wound site and, whilst he was now recovering, he still did not feel ‘quite right’:

"My own doctor is going to put me down for physio but the surgeon said that might not even help. If it hadn’t have been for the physio I think I would have been back in work in 8-10 weeks, but as it is I haven’t been back to work. My granddaughter who is 1, I can pick her up, but after a while I ache. The oldest one who’s 3, I can pick her up but I can feel all my muscles pulling when I do. So I know it’s not right and I’m looking forward to going back to see the surgeon soon.

I’ve had 3 cuts now on the same side. It’s still a bit tender from the last op before Christmas. I sneezed a lot the other day and it was sore afterwards. And around my left hip it’s like I’ve had some Novocain there and it’s not quite worn off yet. My groin was initially a bit tender to touch for a while but it’s getting better. I feel annoyed really, not with the hospital or the surgeon but I’m annoyed with myself for saying yes ok to the physios, I’ll get out of bed."

(D11, father, final interview).
D7 and D8 had experienced intermittent discomfort and pain in their wound sites, particularly on exertion. The surgeon had advised both to consider having their internal sutures surgically released. However, D7 wanted to wait for another few months to see if the problem would resolve itself before considering surgical intervention. But, as D8 found the pain unbearable at time, she decided to have the procedure performed in the hope that it would alleviate the problem:

"I was fine, no trouble at all and then I started to have a lot of pain in my left side. So the consultant saw me and said there probably is something wrong, we'll release the internal stitches. So I had it done on July 1st. I ended up with 2 incisions into the one that I've already got. And they fiddled and fiddled about in there for ages, and this was all under local and I felt a lot of it. It was horrible. But it got rid of the pain (laugh). And since then I've been absolutely fine."

(D8, mother, final interview).

Recipients of donors who had experienced problems were very concerned about their well being and some felt guilty that their donor was suffering.

R9 initially made a very good recovery following his transplant and had returned to work prior to his 3 month interview. However, since the transplant he had suffered from persistent problems with the ureter in his transplanted kidney. It was thought that the ureter may have been damaged during the original transplant and, consequently, it was now restricting the flow of urine, and hence electrolytes, from the kidney to the bladder.

Several temporary stents were therefore inserted into his ureter in an attempt to rectify the restriction. Whilst these temporarily resolved the problem, soon after they were removed the problem returned. Consequently, his recovery had often
been turbulent, requiring several hospital admissions, and both he and his family, particularly D9, found this upsetting and stressful.

Several weeks prior to his 10 month interview, R9 was readmitted to hospital for a major surgical 're-plumb' of his transplanted kidney and he now felt and looked much better:

"It's been an up and down year really, but hopefully it's sorted out.... I'll be honest, for the first time since I started having problems I'm really quite... optimistic and confident about it. Partly because they've re-plumbed the kidney now and that looks really good. There's still a stent in it but that's only a stent to hold 2 bits of tissue together until it's healed, so there should be no narrowing there. So hopefully they have solved the problem, which was causing the creatinine to go up, so really I'm really optimistic and positive.

After they took the last stent out I had to have a nephrostomy put in for a few weeks to relieve the pressure on the kidney. But that got infected and was making me feel ill. So I was admitted to hospital for IV antibiotics and it was then touch and go whether they'd do the operation on the Wednesday, but they did go ahead and do it.

The operation was completely great. Within a couple of days I was up and feeling really good and a week after the operation they checked me out. Since then I've been feeling great, you know, I seem to be getting back to normal, although I've probably lost about 10 kilos since May. So I'm trying to put some weight back on, at least 5 kilos anyway (laugh)."

(R9, husband, final interview).

7.4 The impact of the transplant on donors and recipients

All recipients were happy with how their personal and family lives had improved since the transplant. Even R9, whose recovery had been problematic over the last several months, was pleased with how his life had generally improved, particularly when he was not experiencing complications. Consequently, all recipients were very appreciative and grateful to the donors for donating a kidney to them.
Some recipients became emotional when discussing this and some found it hard

to articulate just how they felt about the donor’s actions. R7 described the
donation as ‘the most marvellous thing that anybody has ever done for me’.

"Since the transplant I’ve been on a high, dancing around like an idiot.
It’s been very positive for both of us. He knows how I feel for what he’s
done for me. He’s delighted that I’m now better and the future is brighter
obviously.

But I know he did it for a reason, he knew the consequences, but I do
think, goodness me, what’s he done for me? This is part of him he’s given
away. He now has only got one kidney…. It’s something that’s in the back
of your mind. It’s wonderful and it means our life together… even if you
have a shorter life together… it’s just lovely. You can’t really describe it.
There’s a joy there all the time and there is gratitude. So you just feel a
very lucky person, very grateful that the opportunity is there…. It makes
you feel humble as well, I think."

(R1, wife, final interview).

Donors were also delighted with how the recipient’s lives had improved since the
transplant and, consequently, felt a great sense of personal satisfaction from
having donated. No one regretted donating, even donors who had experienced
problems post-transplant. The effects of the transplant on the lives of recipients
and their families also helped to confirm to donors that what they had done had
been worthwhile:

"I felt at the time that it was the right thing to do and I feel the same now.
I feel very proud to see my sister so much better. Her health has
massively improved. I can see how much it has improved their life now
and also their two boys. You know there’s been a massive improvement in
their lifestyle and that’s invaluable, if it’s a year, 5 years, 20 years, it’s a
really good thing.

I think the way I still feel about the whole thing, and what I’ve gained
from it personally and what my sister has gained from it, far outweighs
any possible concerns that I have. It’s quite a big thing to feel so
instrumental in improving somebody’s quality of life. That is something
that I can fall back on, you know. Like sometimes in work when you are
bothered about things or financial things you think that it’s quite a good
grounding then and it helps to keep things in perspective."

(D4, brother, final interview).
However, because of the transplant, and how donors and recipients now felt about it, many believed that there was a potential for the tenor of their relationships with each other to be affected. For example, recipients were particularly aware that there was a potential for them to feel 'indebted' to the donors for what they had done for them. However, despite feeling appreciative of the donor's actions, none of the recipients felt 'indebted' or 'beholden' to them. Furthermore, no participants felt that the transplant had caused any problems with, or deterioration in, their relationships with each other. Whilst some felt that they had become closer since the transplant, most felt that their relationships hadn't really changed in anyway.

Recipients felt that this was largely due to the donors and how they behaved with them before, and particularly, after the transplant:

"I've got this incredibly, amazing thing. You can't express how amazing it is and I want to ring [D4] everyday and thank him. You know if it wasn't for my brother I wouldn't have had this chance at all.... It is really the difference between being alive and dead. I can just do more things like run and swim and that is fantastic. He's enabled me to enjoy happiness.

I think it's quite easy to forget the enormity of what he decided to do. The courage.... It still doesn't take away that enormous gamble that he took, and it was a gamble, I felt that if things had gone wrong or if it hadn't worked it might have disadvantaged his health. I just feel like lifeboat men go out and risk their lives. I would like to think that I would have had the courage to do that for someone, but to actually have gone through with it I think is... amazing.

I know I've been to reunions and some of the donors shrug it off, maybe that's how they feel, but I still think it's an incredible thing to do. It involved enormous courage and guts. With my brother especially, because he hadn't had any previous illness or experience with hospitals, or physical pain. It's something almost beyond belief.

He's come out of the experience very well and because of his lean on it and attitude, that's what has really helped me. I think on reflection, maybe he was the right person because he's in no way at all made me feel
guilty about it or.... He's very humble and unassuming. You can't thank someone enough, but there's no obligation from him, no pressure or anything like, oh for God sake, look what I've done for you. He's just continually pleased and excited for me and that's great, because I think, Christ he did that for me. I'm really going to work hard and make something of it.

I think that maybe there is a potential for me and people like me to feel beholden to the donors for what they have done. But I think it's the donor's attitude and the way they behave with you after the transplant that allows you to get on with your life without feeling... well without feeling indebted to them. I think because most donors don't feel that what they have done for you is particularly brave or heroic or exceptional in anyway, and they don't expect us to feel beholden to them, allows us to move on without feeling awkward or... feeling that you owe them something for the brilliant thing that they've done for you."
(R4, sister, final interview).

Throughout the series of interviews, including the final interviews, donors downplayed their actions and did not view donating a kidney as exceptional or heroic in any way. Many also emphasised that they didn't feel that the recipients owed them anything for the transplant:

"I don't think in any way she owes me any sort of debt or whatever because of it. It's just something that I've done. It's like her saying can I borrow the car and I've said yeah, here take it (laugh)."
(D1, husband, final interview).

Also, despite the way in which donors and recipients now felt about the transplant and how it had affected their lives, most tended to no longer have any profound discussions about it. The reason for this was that, for donors especially, there was a belief that it was now time for everyone, especially recipients, to 'move on with their lives':

"I think it's best not to keep talking about it... you know, you don't want to keep bringing it up. I mean it's over and done with isn't it, why keep bringing it up? I don't think there's any point in keeping going over it. It's something that we've done, it's benefited both of us, so why go on about it? I think it's important that you get back to normal really. Also, I think it's important for him, I mean he doesn't want to keep being reminded of the fact. You know, you wouldn't want him to feel that he's..."
beholden in any way. So I think that actually you wouldn’t want to keep bringing it up in conversation.

As I say he’s done well, it’s worked so well, I’m perfectly fine – you know for literally a couple of weeks, and that’s all it was, the discomfort, it’s not a very big thing really, with the benefit of hindsight. I think we did quite a lot of talking at the time, so I think you run out of things to talk about, you know, it’s time to move on.”
(D7, wife, final interview).

7.5 Concerns for the future

Whilst participants were now generally happy with life, many still had concerns about the future. For example, some donors and recipients now felt a greater awareness of the need to ‘look after themselves’ more, by exercising, staying well hydrated and avoiding potential sources of infections.

D6, the only female donor of childbearing age, was a little concerned about the prospect of conceiving a child now that she only had one kidney, although she had previously thought that she did not want to have children:

“The only side of being a woman and having the operation is that it would be a real worry for me to have children now. It probably wouldn’t be recommended for me to have children and I’m getting to the age where probably I wouldn’t have.... I’ve said to the consultants that I really wasn’t going to, but that would be the only slight worry. If anything happened that way whether it would be a health risk to me, but it’s not something that concerns me significantly, I mean it’s not something that’s likely to happen.”
(D6, wife, final interview).

However, the most common concern, particularly amongst recipients, was the fear that the transplant would eventually fail. All recipients were concerned about this prospect and all generally dealt with the possibility of graft failure in much the same way:

“Anything that he’s given me is now going to be a rejection game. But I don’t think about it, I just think that’s a stupid waste of time. It’s working
beautifully and if it breaks down then it's.... You've got to have it in the back of your head because if it happens and you weren't prepared for it, it would probably be heart breaking.

But life goes on and I really believe that you've got to make the most of it. I feel that if I've got 2 years good life out of it then it's been worth it as far as I'm concerned. So no, I don't worry about it at all." (R1, wife, final interview).

Family 9 were concerned about D9's general health and well being. They were both mainly concerned about if and when his problems would resolve and allow him to get back on with his life. However, following his recent operation, both were now optimistic that his condition and, consequently, their life together would improve:

"I just hope that everything settles down soon and we can get back to normality, because I think that is quite important. My only concern is for him really that after having been through all this that it settles down and he can get back to his job and things. But hopefully the surgical bit now has been rectified and it will be ok." (D9, wife, final interview).

7.6 Service issues

Participants focused on three main aspects of service provision in the final interviews; service issues in general (e.g., care, staff and equipment), information provision and follow up care.

7.6.1 General service issues

Whilst some concerns were raised, all participants were generally happy with the transplant service provided by the transplant centre and, if they lived further afield, their local renal unit. All health professionals at the transplant centre were praised for their care and support, particularly the live transplant co-ordinator, the live transplant surgeon and the consultants.
Some families were so happy with the care and treatment that they had received that they now wanted to 'give something back to the service'. Several families were planning charity events, such as discos, to raise money for the hospital staff and equipment.

Even families who had experienced problems post transplant were happy with care and support provided by the transplant team:

"I really don't think you can fault them, everybody is phenomenal. The transplant coordinator, when he was in last time, was really upset because he looked really poorly. I think it's disappointing for them as well. You see them a lot, which is great, because it's very welcoming when you come. They obviously care a lot and when it all goes belly up it is upsetting for them as well. It's quite amazing that they get so involved.

But it is nice. I like coming up here and it's nice to see people. I can't say enough about the back up that we've had from here and how good it's been. The medical side and everything is tremendous really, 10 out of 10."

(D9, wife, final interview).

However, R9 commented on the limited availability, at the transplant centre, of suitable scanning equipment required for the radiological assisted insertion of renal stents. He commented that some people had to wait up to 10 days, often as an in-patient, for this machine to become available, and were then often discharged the same day as the stent was inserted. He felt that this was unnecessarily 'blocking beds' and, whilst he accepted there was a resource issue, he felt that if more scanning machines were available, more hospital beds could be freed up sooner.
Also whilst he was, generally, happy with the service that he had received, he did raise some concerns about his last admission to hospital when he underwent surgery:

"When I was last admitted there was a bed shortage so I didn't go to the kidney ward, I think I went to a normal surgical ward and I don't think the nursing staff there really knew much about transplants. I had to keep asking for my medication, they didn't give me any food or fluids for 2 days and I later found out that this wasn't even necessary.

The staff were nice enough but, probably through no real fault of their own, I don't think I was looked after with the same expertise as I would have been on the kidney ward. I think it is important that when you are admitted in this way that you get the specialist care that you need, especially the anti-rejection drugs and I think you can only get that on the right wards."

(D9, husband, final interview).

Family 11 were also happy with the transplant service and felt that D11's operative complications were 'just one of those unfortunate incidents'. However D11 was still very unhappy with the care he received from the physiotherapists whilst in hospital and he blamed them entirely for his wound problems. He had made an official written complaint about this incident to the hospital and was also seeking legal advice on this matter.

7.6.2 Information

Participants were generally happy with the provision of information before and after the transplant, although some would have liked to have received more information about things such as possible side effects of anti-rejection medication (e.g., weight gain). Participants again reiterated how informative and useful they found they found the live donor information evenings.
The evenings were a major source of information for families and everybody who attended an evening found it to be helpful and supportive. Several participants had also volunteered to attend future evenings to speak to prospective families. All recommended that families attend an evening.

7.6.3 Follow up care

All recipients were happy with their level of follow up care from the transplant team. Most recipients were now being seen every 4-8 weeks and this decreasing frequency between follow up appointments helped to reassure them that they were slowly 'getting back to normal'. Many also felt that the less they had to attend the hospital, the more control they gained over their own lives:

"It's been great where I had spaced out appointments. It's more a formality now and I'm getting back into a normal living. The whole regime of being on dialysis your life revolves around hospitals. That's changed now and I'm back to the person I was, the independent self, that I was before."

(R4, sister, final interview).

All donors felt that their post-transplant follow up care was limited. However, some were satisfied with this because they felt physically well and believed that if they were not experiencing problems, there would be no real need for them to be seen as frequently after they had donated.

However, most donors were unhappy with their follow up care and felt that it was insufficient, particularly compared with the recipients. Some donors felt neglected and were concerned about the apparent lack of interest in their health and well-being and, in particular, their post-transplant renal function. Some even
felt that the transplant team had treated them like a ‘means to an end’ and were disappointed by this.

"I think the after service for me needs a bit more, you know, because I've got this lump on my side. I've been to see some doctors and 2 said they think it's a hernia and another said they don't think it's a hernia. But nobody has done anything about it, you know what I mean? That's the only gripe I've got really. I don't think it's all that clever. I mean for the wife it's been absolutely marvellous but for me... forgot it. I feel all right, but it's been 6 months that I've been on about this and they haven't done anything.

But when I see the Professor next month I'm going to have a go at him about it. The only thing I'm worried about is this lump. Well I'm not worried about it, it's just the fact that nobody has bothered to do anything about it."

(D2, husband, final interview).

7.7 Family 3’s experiences

7.7.1 Getting back to normal

Since the previous interview, D3 had experienced recurrent pain from his wound site, which resulted in him having to take regular analgesia and prevented him from returning to work for some time. He was eventually readmitted to hospital for a laparotomy under general anaesthetic, where it was discovered that his internal wound sutures had not dissolved properly. In an attempt to alleviate the problem some of the sutures were surgically released.

While the pain had improved somewhat since the procedure, he was still experiencing intermittent cramping like discomfort, although now mostly of a mild nature, particularly when sitting or driving for long periods. He had, however, now returned to work full time and was able to do most activities that he could do pre-transplant. However, as the discomfort had not resolved, his
surgeon had suggested another laparotomy in a few months time if the pain had not settled down.

R3 had also experienced further complications since her previous interview. For several months she was anaemic, had a low albumin level and had experienced several recurrent CAPD catheter related infections, including an episode of hospital acquired MRSA. This resulted in her feeling tired, lethargic and depressed.

However, after several weeks she had started to feel better. She then had a new CAPD catheter inserted and was given prophylactic antibiotics. However, she experienced a severe allergic reaction to the antibiotics, which made her feel extremely unwell. This upset and annoyed her significantly as she felt it was an unnecessary set back and this experience also compounded her depression:

"At the time it was very hard to see beyond what had happened and..... see that there might be a future really.... I think the whole experience I've had with the renal transplant, failure and everything that's happened since has really knocked my confidence very badly.

I went through a very bad patch, I think I saw you just after, where I couldn't see a way through, I couldn't see a future. I couldn't see a future I wanted to have anyway, put it that way.... Things were really bad.

I think the professor was right when he said to me, you are going through a grieving process because you are not the person that you were and you are not the person that you thought you were going to be. So you are grieving for the person that you've lost and the lost opportunity and you're grieving for [D3] because he went through a lot and still does.

It is a bereavement process really but I was physically extremely debilitated as well as having the mental problems of being so far different from where it was intended that I should be; by everybody not just by me. Also I think it was worse for me because all my expectations were positive expectations. Although both of us knew that there were risks, because we are both intelligent people, and obviously we were told that
there were risks and we accepted that, otherwise you wouldn’t do it. All our expectations were that there would be a positive outcome. 

I think the combination of all those factors, particularly the physical side of it and that when I was on haemodialysis I was so ill. When I look back on it, it makes my skin crawl, it was so horrid. And I got to the stage where I just didn’t want to wake up. If somebody had come along and said you can have a shot in your arm and that’s it, it’s all over, you don’t need to worry any longer, I would have had it. It was that bad....”

(R3, wife, final interview).

However, over the last few months R3’s health had improved significantly. She had commenced CAPD and found it to be much better and far less restrictive and disruptive than haemodialysis. It also started to make her feel physically healthier, which, consequently, allowed her to do more things, such as return to work and go on holidays, and helped her to regain some sense of personal control over her life:

“Around May I started to get a lot better quite quickly and I think that was because of a number of things. One was that I finally got to do CAPD and found that it was okay. Then I went back to work part time in June and I’ve had three holidays recently, two in Devon and Cornwall and one in France. We had a really good time, it was really nice.

I couldn’t have contemplated going abroad in May but in a relatively short period of time I sort of felt I’m going to do it, I shall be fine. There are doctors in France and I can speak French, so if things go wrong I’ll manage it somehow and it’ll be all right.

I went back to work gradually and that was like a milestone. It was like, I’m not a sick person any longer, I can pretend to be a normal person and that was quite important to me. I love my job and I really like the people I work with and it’s more to me than just a job now. It’s like me saying hello I’m back. I’ve put this behind me... I’m dealing with it....

Then within about 3 weeks of going back to work we had a week in Devon and Cornwall and we stayed in a holiday cottage, which had footpaths and cycle ways nearby. Before my transplant went wrong we always walked and cycled a lot. When we went there we had a week of glorious weather and I cycled for about 4 days, over 130 miles.... We were cycling along one day with lovely scenery and it was a lovely day, and I thought, thank god I didn’t kill myself (laugh).
When I came back I thought, well if I can cycle 130 miles it doesn't really matter whether I'm on dialysis or not because, while I don't want to cycle that every week, it was a big psychological boost. After that I thought, well I can still enjoy my life, we can still do things that we want to do. The thing is to do them while we can still do them and not sort of hang about thinking, oh I won't cycle until I've got a kidney transplant, because I'm a fit person and I've got dialysis, so why should it stop me from doing what I want to do?

When I became reasonably well established on CAPD in May, and I tell you what it was, you asked about a pivotal moment. The pivotal moment wasn't actually to do with an event, it was psychological, in that I had control over my life again. I don't have to go to a dialysis centre, I don't have to have things done to me, I don't have to be in a clinical environment, I'm not a patient anymore, I'm me.

I know I am a patient but I look after me. I'm responsible for my care and that's how I like it. I can do it when and where it suits me. I'm not beholden to anybody else. I can give my own EPO injections and every 6 months I have to attend a CAPD clinic and that's it... so far. I think when I could see myself coming back... that's when I started to be me again. When we went on holiday I think it was such a relief for both of us... because we suddenly thought, mmm it's ok."  

(R3, wife, final interview).

D3 was also extremely pleased with how his wife's life and well-being had improved since she had commenced CAPD. He was delighted that her health had improved so much that it had enabled her to return to work, go on holidays and resume activities such as walking and cycling. This meant a lot to him, them as a couple, and especially her. He felt, however, that life was generally different to how they had both expected it to be but they were both now getting used to it.

Despite the transplant rejecting, and its associated problems, R3 had started to come to terms with the rejection and had learnt to accept the necessity of CAPD. She was also now determined to ‘move on’ and make the most out of life:

"One of the things my consultant said to me was you have to live your life the way you want to live it otherwise it will pass you by. So that's what I'm trying to do.... So although I've had times when I don't feel so good and I have times when I get a bit down hearted, particularly late at night
when I've got to do an exchange and I'm tired and I just think... it's the final straw. I don't know why, it's only 20 minutes but I think, oh I can't do this and that is quite wearing. But I've kind of come to an accommodation now, which is that I was determined that I would make the best of it and I wasn't going to let it stop me doing what I wanted to do.

But I've had a lot of support, particularly from my family and my local medical team and particularly my Professor and... I've got to the stage where I can live a pretty good life. I don't know how long it will last, but while it does last, and while I've got it, I can get on really.

I just thought that there was only one way out of it and that was to get through it and that's what I did in the end. But I could quite easily see how if I hadn't been lucky enough to have the love and support of my family and a particularly caring consultant... I would have topped myself...."

(R3, wife, final interview).

D3 had found supporting his wife through the experience quite difficult at times. He was, however, pragmatic and supported her as best he could, mainly by reinforcing to her that things would eventually get better and constantly trying to 'keep her chin up' through it all:

"It hasn't been a pleasant experience but it's been an interesting one.... You have to have faith that it is going to get better and we were told that the journey was going to be a fairly lengthy one and there would be lots of ups and downs along the way and there were.... When we get down I just carried on doing what I always did, which was to try and... keep her up there rather than let her go all the way down.

I couldn't have acted in another way because it wouldn't have felt right to me. It seemed to have worked. We didn't fall out (laugh). We probably got used to each other. She was... psychologically ill as well as physically ill. I think, my rational for doing it is that's me and if I had oh deared, I think that would have probably made her worse, because then there would have been no one there with the rope pulling her up the cliff face. I'd have been down there with it and I don't think that would have been good for her. It certainly wouldn't have been good for me.

I didn't really doubt that she would get well but I knew it was going to be a long time. As soon as she felt physically better then psychologically she would recover. When I saw her in a lot of pain you are at the end of your tether and there is nowhere else to go, you've just got to go through it. I think she picked up quite quick actually, psychologically. She could then
They also felt that their relationship had changed, temporarily, to some extent because R3 had been so ill. During the initial few months all of their, and especially her, energy had been put into just getting through the experience of rejection and the associated problems. Whilst this had often been difficult for them, they both now felt that this ‘shared experience’ had actually strengthened their relationship, and, now that the situation had improved, they were both determined to make the most of their life together:

"She clearly wasn’t the person I knew, none of that old spark was there.... That was a damn sight worse for her than it was for me, but... I thought she was going to get well and she did. So it was quite a long time and we found our own way through it together.

We’re probably stronger now than we were before we started, probably through having a shared experience. If you go through something that is grim together you either fall apart or you gain something from it. I think you do take something from it and I suspect that we are probably stronger, as a couple, now, as a result of having gone through that.

She’s stuck at it, she’s got a lot of strength of character. She is every bit as determined as I am. She could have reverted to, oh I’m the patient, something bad has happened to me and I’m going to be unwell because it’s all happened and why shouldn’t I be unwell. Well she did a bit of that I suppose but we didn’t want to be like that so we just got on with it.

[R3] is not like that character wise and when we were on that road it was very uncomfortable because it wasn’t her. But then if I felt like she was feeling I would have been exactly the same. But she’s out of that now and she’s back and she’s determined not to let it ruin her life, and there’s no reason why it should. We’re looking to the future and we’re planning to bugger off to France, if only we could afford to go and live there (laugh). I think that’s good. We’re not dwelling on the past and she does CAPD in the car and stuff on holidays (laugh). We now just take that as normal. I’m happy and grateful that we are able to do that sort of thing.

If you told me 12 months ago that in 12 months time we’d doing exchanges 4 times a day then life might be different. But life is different and it’s something you grow into and get used to."  
(D3, husband, final interview).
7.7.2 Treatment issues

While R3 didn’t particularly like having a PD catheter, or having to dialyse several times a day, she had learnt to accept it, mainly because it allowed her to live her life with relatively limited disruptions or problems. She also felt much better on CAPD than she did on haemodialysis and was now able to dialyse in work, at home and she had even dialysed on a ferry to France and in the car, at night, whilst on holidays.

However, despite the whole experience of graft rejection, F3 both felt that having the transplant had been the right thing to do and, theoretically, they would both do it again if they could:

"You can only make the decisions based on what you know and the information you have access to at the time. Obviously if somebody had said to me look it’s going to be crap, it’s not going to work, don’t do it, I know for a fact I wouldn’t have done it. But on the basis of the information that was given to us, for 2 ½ years before the transplant, so we did have plenty of time to think about it and we did, we never really had any misgivings about it.

So I would make the same decision again, given the same circumstances...."

(R3, wife, final interview).

R3 was also very happy that her husband had donated his kidney to her, even though it hadn’t been successful. D3 had no regrets about donating, despite all the problems that they had both experienced, and, if it was possible, he would be prepared to do it all over again:

"I see it as a positive experience, but I didn’t do it to feel good, I did it for practical reasons. Would I do it again...? If I had the knowledge I now have about that they don’t always work, yeah I’d go and do it tomorrow and I’d go and do it in the same place with the same people.... I suppose why I feel good about it, if that’s the right word, is that there was an
opportunity, there was every chance that it was going to succeed and not to have taken that chance... wouldn’t have been the right choice and I would have felt bad about that.

So part of feeling good is that I don’t feel bad about having taken the risks. I’m glad I did it, it hasn’t worked out the way I really wanted it to, but I’m still glad. I feel good about not feeling bad for not having done it and I would do it again, even with the knowledge that I now have.... I don’t think really it would have been any harder a choice at all.”
(D3, husband, final interview).

Despite the rejection, R3 still felt that a kidney transplant was her best long term treatment option and, consequently, she was currently on the cadaveric kidney transplant waiting list. She had been reassured by her consultant that a robust anti-rejection treatment regime would be initiated should she ever receive another kidney, which made the possibility of another irreversible graft rejection unlikely. However, because of her previous experience, the prospect of another transplant worried her:

“I try to approach it as logically as I can. Certainly my husband would want me to go and my consultant thinks that it’s a good thing to do and he is convinced that I’ll get one. But I don’t sit around by the phone because it’s not right. In fact I’m not quite sure where my bleeper is (laugh).

I have been put off transplants though. I do feel quite iffy about having another one, although less iffy than I did. As time passes I suppose, not that the memory fades because they don’t, but you become more rational I think.... You can conceptualise it more and you can rationalise it more.... You can talk yourself through it a bit more. But I still wouldn’t be jumping for joy if the phone went off now I have to say.

And I try not to dwell too much on the future and the possibility of a transplant, not because I don’t think that it won’t happen, but you can waste so much time thinking, oh well when I have a transplant, or what if I don’t have a transplant and I get really ill. You can just disappear into worry land. So I do make stringent efforts to hold my mind in check....”
(R3, wife, final interview).
7.7.3 **Service issues**

F3 were generally happy with their care, support and follow up care from the transplant centre, their local hospital and their local dialysis unit. In particular R3 praised the care and support provided to her by her consultant at her local hospital. They both still felt that the graft rejection was ‘just one of those things’ and that everything possible had been done by the medical team to try to save the transplant.

However, D3 felt that there was a need for improved levels of post-discharge information for recipients and, in particular, donors. He felt that information leaflets and/or booklets were required to provide details about the recovery process.

R3 still questioned whether she could have been better prepared for rejection by the transplant team. She still believed that the health professionals had been overly optimistic about a successful outcome and, whilst potential complications such as rejection had been discussed with them, she felt that not enough attention had been paid to such issues. However, she did feel that her opinions about this were influenced by her experience:

"I always believed that if we got through the work up it would be fine. So by the time we got to the end of that, and I think it's very much geared to that, I think the doctors and the transplant coordinators start off being very cautious and you as pass each hurdle, it becomes almost a self fulfilling prophecy. Then there's an assumption that it will be fine because that's been their experience, I suppose.

I think they were a bit ingenuous in terms of everything will be wonderful, but that's probably just my slant on things because of what happened to me. But that wouldn't have altered the decision I originally made...."  
(R3, wife, final interview).
R3 was also still very critical about the emotional support that she had received from the transplant team, in particular the psychologist, after she had been discharged from hospital. Whilst she had been offered support by the psychologist, she felt that it had been offered in an unsatisfactory way. She therefore felt that this aspect of the transplant service needed to improve to ensure that future patients were better supported than she felt she had been:

"When I went a bit loopy I had an answer phone message saying this is the renal psychologist, if you want to talk to me you can ring me up. But the very last thing that people who are in the state that I was in do is ring people up and tell them. You sit on it and you fester and asking for help is the last thing that you can do.

I think probably what I wanted was for somebody to show some interest really. Like how are you getting on? Is there anything we can do? Is there anything that you want to know? And nobody really did. I didn't even know the psychologist so I couldn't just walked into her office or sit on the end of a telephone and talk to somebody who I've never met and say I'm thinking of killing myself. You don't do that.

When things go badly wrong what you really want is for somebody to ring you up and say I'm coming to see you next week to see how you are getting on. I know they are busy people but no bugger ever did. I think considering the effort that went into the work up and the support you can get after you've had a successful transplant ... there was nothing....

I was cross that she just left a message on the answer phone. I think, as a professional, the least you can do is speak to the person not just leave a message. I would have pursued that, you see, because, you know, she hasn't rung me back. Is she not answering the phone? What is she doing? Is she lying in bed crying all the time, which I was? I would have pursued that and I think I would have actually talked to somebody if they'd taken the trouble to get hold of me. I really wanted someone to talk to who wasn't my husband, because I can't go on weighing him down, because he had the daily responsibilities of looking after me because I wasn't able to look after myself. And he was recovering from a major operation as well.

Even if I'd said to the psychologist look I don't want to talk to you because I don't know you but please can you ask so and so to come and see me, because I can't travel up to the centre. Someone that I know that I can just sit and work my way through a box of tissues. That would have helped a lot.
In fact what eventually happened was that my poor old Professor copped it and he's probably still washing his shirts now. He was just a star and all I could do was cry, for about an hour with patients stacked up outside his clinic, and he just sat there with the tissues...." (R3, wife, final interview).

7.8 The interview experience

This study involved recruiting and interviewing participants at an emotional and demanding time in their lives. Many pre-transplant interviews were conducted several days before donors and their recipients were due to simultaneously undergo a major surgical procedure. Post transplant interviews, particularly at three months, were conducted when participants were recovering from the procedure and readjusting to post-transplant life. At the first follow up interview, family 3 had also recently experienced an extremely upsetting and unanticipated episode of acute, irreversible graft rejection. Consequently, their first post-transplant interview was incredibly emotionally demanding. Each interview lasted over an hour and, during this time, I discovered that R3 had been so depressed about her transplant failure that she had contemplated suicide several weeks earlier and was, at that stage, being treated for depression by her GP.

The longitudinal nature of the study resulted in considerable participant self disclosure, at three separate intervals, over a period of a year. The topic area explored was also generally emotive and, therefore, all participants shared many personal, and often distressing, thoughts, feelings, concerns and experiences. Furthermore, some participants became emotional or upset whilst being interviewed, although no one wanted to stop any of the interviews.
However, whilst I felt that participants would probably not personally benefit from participating in the study, I also felt that some of the interviews may have had an 'unburdening' or 'cathartic' affect on many participants. I therefore felt that it was essential to establish why participants had participated in the study and how they had experienced the interview process.

Consequently, at the end of the final interviews, all participants were asked and consented to discuss their experience of participating in a series of qualitative research interviews. All donors and their recipients were interviewed together (except family 4, who were interviewed separately as they lived so far apart). The interviews were recorded and transcribed verbatim and the data were analysed using the same process as the other interview data. I found that:

Some participants had consented to the study because they believed that they might learn something. However, most had participated for altruistic reasons; that is, they believed that the research could somehow help other families:

"The nice part of being involved is to maybe help other people through it. So somebody else could read the research paper...because we've been helped by other people talking about things."

(D6, wife, final interview).

Although all participants were willing to be interviewed, some had initially felt uncertain or anxious about participating:

"I thought it would be a bit of a chore in a way, a bit of an ordeal to sit down and talk about it. But, no, I've actually quite enjoyed your visits."

(R7, husband, final interview).

One participant felt the interviews gave her 'permission' to talk:
"It [talking about the transplant] feels a bit self-indulgent sometimes, and I think being able to participate in some research gives it a bit of credibility... It [the interview] doesn't feel self-indulgent actually...and it does help to talk about it.... We've quite enjoyed it."
(D7, wife, final interview).

Indeed, many participants were grateful for the opportunity and dedicated time to talk about their experiences, as many, for whatever reason, had not found the time to do this in the normal course of their lives:

"I do think you get a benefit out of just being able to talk through the process. It has been beneficial in that way because sometimes I think we don't talk."
(R7, husband, final interview).

Most participants thought it was helpful to talk to someone who was interested in what they had to say and would probably understand what they were going through:

"You keep these things to yourself...because there's no one you can tell it to. It's no good telling it to your daughters because they don't understand, whereas you do understand. So when we tell you how we are feeling you probably know to a certain extent what we are on about."
(D1, husband, final interview).

R3 found her three month post-transplant interview difficult as it was undertaken at a particularly difficult time in her life:

"I found the first interview no problem at all. I found that quite easy. When you came the second time, for me, that was quite difficult because it was still very close to all the horrid things.... It was difficult to go back over it and kind of put it in a sensible way that wasn't overtly emotional. But, having said that, I found it very, very useful really."
(R3, wife, final interview).

However, none of the participants expressed concern or regret about taking part in the interviews and most felt that the process had actually been helpful or part of a 'healing process':
"I've said things to you that perhaps I haven't even said to my wife. It's been quite cathartic. It's actually been enjoyable and quite helpful for me as well.... I'm pleased that, through our experiences, it has helped the research...that to me is a bonus."

(D3, husband, final interview).

7.9 Conclusion

This chapter has presented data from interviews conducted at 10 months post-transplant. In the subsequent three chapters, data from all three phases of interviews are interpreted and discussed.
CHAPTER EIGHT: Data interpretation and discussion of findings: Service provision issues

8.1 Introduction
In the previous three chapters, data from the three phases of interviews were presented. In this chapter, participants' experiences of service provision throughout the live transplantation process are discussed. Specific areas explored include; general service issues, information provision, two centre care and follow up care.

8.2 Service provision issues
A key aim of this study, primarily because of the lack of existing empirical evidence, was to explore participants' experiences of service provision throughout the live transplantation process.

Data about service provision issues arose during all stages of interviewing. However, despite talking about the live transplantation experience, very few participants, at any stage, talked spontaneously about the transplant service. Consequently, participants who did not discuss this aspect spontaneously were asked 'how have you found the transplant service throughout this process'? Responses were then followed up accordingly.

In this chapter, several key themes that arose from the data are explored; general service issues, information provision, emotional support and care, two centre hospital care and post-transplant follow up care.
8.3 General service issues

The findings show that the transplant service was generally well evaluated by participants, regardless of clinical outcome. In particular, staff, especially the live transplant co-ordinator and consultant surgeon, were praised for their care and support. Some families were so pleased with the service they had received that they now wanted to 'give something back' to the transplant unit as a way of saying 'thank you'. For example, Family 1 were organising fund raising events to buy a new carpet for the nurses' lounge.

From a service perspective, participants' positive accounts are both encouraging and laudable. However, various other significant issues were raised about service provision, both positive and negative, that require further consideration to facilitate future service development.

The pre-transplant donor assessment process was particularly lengthy, often lasting several months before suitability to donate was finally established. All donors recognised the necessity of this evaluation, although many found the timescale frustrating because they 'just wanted to get on with it'.

The importance of this assessment process must not be underestimated, as it ensures donor-recipient compatibility and establishes suitability to donate, thus increasing the likelihood of a good clinical outcome (Veitch 1996, Hiller et al 1998, The Amsterdam Forum 2004, Wafa et al 2004). However, the process also serves another significant purpose for prospective live donors. That is, it provides them with sufficient time to properly consider their decision to donate (Sadler...
Whilst virtually all donors made an instantaneous, voluntary decision to donate with little or no deliberation, D4 spent several months, after initially volunteering to donate, considering his decision. The assessment process provided him with a valuable contemplative period and allowed him to eventually reach an informed decision to donate:

"The first few months I spent undergoing a sequence of tests. At the end of each phase you'd sort of pass a milestone in your compatibility testing, and I think that is quite important. It's very sequential and quite structured and gives you a few months of... consideration time, before you even know that you are compatible. And that's quite useful.

I eventually came to the view that it was the right thing to do, because I reached a firm conviction that it was what I wanted to do. But there was a period of a couple of months where, I suppose, I was a bit unsure. And I think that the length of the process, the fact that you have this sequence of tests that have a certain period of time in between, is quite good, because it allows you to think."

(D4, brother, 1st interview).

The findings suggest that the pre-donation evaluation process should not, therefore, be significantly accelerated or curtailed in any way. Health professionals, especially the live transplant coordinator, should also always be available to discuss concerns with prospective donors, particularly those who are unsure about their ability to proceed with the transplant.

Furthermore, throughout the assessment process, prospective donors should not be put under any pressure to donate by medical staff (none reported any such pressure in this study) and must be aware that they are free to withdraw from the process at any time, without prejudice (Calder and Chang 2004, The Amsterdam
Potential donors should also receive assurance that medical and/or individual reasons for not proceeding with donation will remain confidential (The Amsterdam Forum 2004) and, if necessary, a 'face saving' medical reason (i.e., a plausible medical excuse) for withdrawing from the prospective transplant should be provided by the medical team (Caplan 1993, Calder and Chang 2004).

Family 7's scheduled transplant was postponed due to a delay with their ULTRA application, causing disappointment and distress. Consequently, F7 suggested that the application process needed to be reviewed, although they were unsure how the process could be improved. However, since this incident, the transplant centre now routinely submits all genetically unrelated applications to ULTRA via a courier service and no further problems have been reported. Currently, ULTRA is also scheduled to be replaced in 2006 by a system of professional, independent third party assessment (e.g., by a consultant or a psychologist).

Some participants experienced unnecessary post-operative pain due to problems with their analgesia devices:

"Because I was in such agony I was using the morphine PCA every 5 minutes and then I started to feel sick. So I didn't get a great deal of pain relief really, especially as the pumps didn't work properly. The only person who could get the pump working at night, which was when it went off, was the pain nurse and she wasn't on duty at nights. So every night the pump kept going off and making a noise and waking everybody up. The nurses would fiddle with it, but not really get it going. And there was lots of conjecture about why it wasn't working, whether it was because the syringes were cold or whether it was the pumps. The Professor saw me afterwards and said would I write some comments and I put that as something that needed attention."

(D7, wife, 2nd interview).
It is unclear what the exact cause(s) of these problems were. However, it is unacceptable that patients experience unnecessary post-operative pain either because equipment does not work properly, and/or because ward staff do not know how to operate them correctly. There are a variety of issues that NHS Trusts have to contemplate when considering the need for further staff education and training or purchasing and repairing equipment. However, to ensure that future patients do not experience the same problems, the hospital needs to establish the cause(s) of these problems and resolve them as a matter of urgency.

8.4 Information provision

Participants were generally happy with the provision of information, pre and post transplant, and with staff's ability, particularly the live transplant coordinator, to answer their questions promptly, by phone or in person. Providing participants with relevant, accurate, up-to-date and understandable information is a fundamental element of the informed consent process (Nolan 1999, Olbrisch et al 2001) and can also help to reduce anxiety levels (Callaghan et al 1998, Watts and Brooks 1997, Scott 2004).

A small-scale German study by Schweitzer et al (2003) found that lack of information increased participant’s anxiety and, in some cases, resulted in donor-recipient couples postponing or even abandoning their prospective live transplants. Furthermore, those who did proceed, despite unresolved concerns, were found to be at a higher risk of more complicated outcomes (Schweitzer et al 2003).
Participants did, however, raise a number of issues about information provision. For example, whilst they were happy with the level and content of pre-operative information, some donors felt that it should have been provided earlier than the night before the operation, especially information regarding post-operative pain management. They felt that this would have resulted in them being better prepared for the post-operative period and more able to make informed decisions regarding analgesia options. Similar findings were reported in small scale studies by Burnapp (1998) and Peters et al (2000).

Providing pre-operative information at an appropriate time and in a manner that suits all families, without causing information overload or undue anxiety, is an extremely difficult, if not impossible, task for health professionals (Hughes 2002, Garretson 2004, Scott 2004). However, incorporating basic operative information into an admission leaflet or booklet (and making it available to those who want it) prior to providing more detailed verbal information, has been found to be an effective method of preparing patients for elective, general surgery (Watts and Brooks 1997, Garretson 2004, Scott 2004).

This approach would seem to be particularly appropriate in this situation, since many participants felt that there was a need for more structured, up-to-date information leaflets or booklets to be developed, to support existing information provision, particularly regarding pre-operative and, especially, discharge information:

"If I could improve the situation I'd like to know more on discharge, because on discharge you are not told what the normal range of expectations is, which makes it much harder to cope. Every time you've got a symptom you think, oh God is this the end or something? It should
be fairly straightforward to sit down and go through the normal range of things that could happen. You just don’t get anything really. The assumption being that if it does happen you’ll find your way to your GP. Well that just takes up their time if it’s within the normal range. That would be one way of trying to improve things.”

(D3, husband, final interview).

An Australian study by Henderson and Zemike (2001) found that general surgical patients who had received comprehensive discharge information, particularly about wound care, pain relief and recovery, had less concerns and were less likely to access a health facility after discharge (if their recovery was progressing normally) than patients who had received no information.

The live donor information evenings were the major source of information for participants. Most had attended one of these evenings and all found them to be extremely informative and beneficial and provided them with an opportunity to have their questions answered by clinical experts.

However, families appeared to derive far more from the evenings than just information. As Hilton and Starzomski (1994), Eggeling (2000) and Stothers et al (2005) also discovered, participants found having the opportunity to speak to families who had already gone through the process an extremely helpful way of preparing for transplantation. They were able to provide participants with a unique personal insight into the actual process that could not be provided by health professionals. Both donors and, especially, recipients found this reassuring, as it helped to allay concerns they had about the impending transplant:

“We spoke to one lady who had just donated... and that was very positive because it was only a matter of weeks before she was back on her feet.
again and I think that was quite reassuring for my wife. It was very useful to be able to talk to a donor.

It made me feel a lot easier because you get it into your head what the surgeons have said to you, that the operation is not very comfortable for donors, she could be in pain for up to a year. I'm sure they always give you the worst case scenario, but that's their job. But it was nice to speak to someone who had actually been through it and to find it wasn't quite that bad, well for her anyway. I know each case is based on its individual merits really and everybody is different. But it was good for me in a way, because I felt maybe it's not going to be too bad for her.”

(R7, husband, 1st interview).

Previous studies (e.g., Hilton and Starzomski 1994, Eggeling 2000 and Stothers et al 2005) have only discussed the benefits of information programmes for prospective donors (and often their families). The data in this study, however, demonstrate the benefits of such programmes for potential recipients. Consequently, offering prospective recipients, as well as donors, the opportunity to meet other families who have already gone through the process, to share their experiences, should be recognised by transplant centres as an important and helpful way of preparing families for live transplantation (Burnapp 1998, Hiller et al 1998, Cabrer et al 2003).

Participants made a number of recommendations for future information evenings, most of which were already common practice. For example, many believed that the timing and frequency of the evenings were important and that, therefore, they needed to be held regularly throughout the year so that prospective families had sufficient opportunities to attend one at the most appropriate and beneficial time for them. Also, if possible, sufficient numbers of ‘live families’ should be invited along so that everyone attending had the opportunity to speak with them.
Finally, the choice of ‘live families’ invited along to the evenings was believed to require careful consideration. For example, inviting donors or recipients who were frail or elderly may seem laudable from a ‘if they can do it, so can you’ perspective, but it can actually be counter-productive:

"The chap invited along came in with rheumatoid arthritis on walking sticks (laugh). I just didn’t think it was very well thought out. We thought, oh my God, look at the state of him. We hoped to see someone looking fit and well. We did get to speak to him, but he was very shy and quiet."

(D10, wife, 1st interview).

F4 and R3, both of whom experienced episodes of acute graft rejection (R3 irreversibly so), questioned the balance of information presented at the evenings they attended. D4 also questioned the types of families invited along to discuss their experiences. Whilst they felt that the information presented was balanced, they believed that not enough serious attention was paid to potential complications, such as graft rejection. D4 felt that the ‘live families’ invited along all generally appeared to have experienced few, if any, complications. Consequently, they felt that this was not a true reflection of reality and that, if future evenings were to be truly informed, these issues needed to be addressed.

R3 also questioned whether she could have been better prepared to cope with graft rejection if she had been better informed about such issues beforehand:

"I’m not sure it would have made any difference to be honest, because we did know there were risks attached and a possibility of failure. But I do think, and this is because my view is skewed by what’s happened, that when we went to a live transplant evening everyone was really positive and upbeat. The whole question of things going wrong was just skimmed over and I can understand why that is, because it’s a huge thing for the donor and the recipient.

But although we knew about things like post-operative complications like clots and things, I never really entertained the thought that I would have such a catastrophic rejection. I knew that people with transplanted
kidneys have rejection episodes but the whole tenor of it was, we can cope with these. But it never got stronger than that, so when it did happen we were entirely unprepared.... I don't think its complacency, I just think that I might have been better able to cope, or I might have not been so devastated if... that had been introduced in a kind of fairly serious way, rather than just everyone has a couple of blips.

*I think that not enough was said about the possible downsides. But it's a bit like being told you may reject, you think, oh it wont be me, it'll be somebody else. But you need to know these things, because otherwise how can you make an informed choice? While it wouldn't put me off it might put other people off.... I mean you don't want to go to an operation being told the catastrophic things that can go wrong, but on the other hand you need to know that it could. I think it may be an effort to jolly you along, if you like.... There's an assumption that it will be fine because that's been their experience, I suppose.*

(R3, wife, 2nd & final interviews).

It is essential that if families are to make truly informed choices about live transplantation, they need to be presented with balanced, accurate information, including details about potential complications, such as graft rejection (Lumsdaine 2000). I attended an information evening, soon after data collection, for research purposes and, from a clinical perspective, found it to be extremely objective and well-balanced. All speakers, especially the live transplant coordinator and surgeon, properly acknowledged the benefits and complications of live kidney transplantation, especially acute and chronic graft rejection.

Whilst a variety of 'live families', including those who have experienced common post-transplant complications, should be encouraged to attend an evening to discuss their experiences with prospective families, the transplant centre does rely completely on the willingness of such families to volunteer. Consequently, who attends and the type of experience they have had is essentially beyond the control of the transplant unit.
However, would families, such as F3, who have experienced irreversible graft rejection, really want to talk to prospective families about their experience, as D4 suggested might be useful? It is, I believe, questionable whether such an encounter would be in their best interest. Furthermore, given the relative rarity of graft failure, should prospective families be subjected to such encounters? Consequently, whilst potential complications must be discussed with prospective families (The Amsterdam Forum 2004), I believe that it would probably be best for all concerned if health professionals alone continue to discuss such issues.

It is also questionable whether information alone (or any other intervention) could properly prepare a person for graft rejection. As R3 admitted, because of the success rate of live transplantation, there was, perhaps, a tendency for recipients to think, even if they were in possession of the relevant facts, that 'it probably won't be me'. Consequently, if irreversible graft rejection was to occur it would be extremely devastating because it was not really expected or anticipated.

This would appear to be particularly relevant in this study because R3 contradicts herself between interviews. Whilst she said that she felt that she may have been better able to cope if the topic of rejection had been discussed more thoroughly pre-transplant, she actually said in her first interview that these issues had been properly addressed by the transplant team:

"The single most useful thing that we've been to was the live transplant evening. It was... a completely positive experience. I know that there are people for whom this hasn't worked and they were open about that. (R3, wife 1st interview)."
Other studies have also recognised the benefits of information programmes, but it should also be acknowledged that, for whatever reasons, such forums may not be for everybody. For example, R9 did not want to attend an information evening, despite being aware of what it would entail, because he felt that it would be 'like a sick club' that he did not want to be part of. But, given the reported benefits of such programmes, the findings suggest that all prospective families should be offered the opportunity to attend an evenings at their convenience, and they should be made aware of the potential benefits of attending. They can then make an informed decision about whether or not to attend.

However, as some participants may not want to attend an information evening, it should never be the sole source of information, even if it is the main source. Other forms of written and verbal information should also be available to participants who do not wish to attend an information evening.

8.5 Emotional support and care

Participants were generally happy with the emotional care and support provided to them by the transplant team throughout the live transplantation process, particularly from the live transplant coordinator. While in hospital, donors and their recipients were usually kept in the same ward bays as each other. All participants found this to be beneficial as it allowed them to support each other and follow each other's progress throughout the process. This was particularly important to participants just before surgery and in the immediate post-operative recovery period.
This was, however, extremely important for Family 3 because they were subsequently able to support each other through a very difficult period:

"The ward staff were good but it was fortunate that [D3] was there, because we were mutually supportive of each other. If I'd been on my own, if I'd had a cadaveric transplant for example, I think I would have been much more reliant on staff and I think I would have found it even harder. But because my husband was there... without him I think I would have gone bonkers."

(R3, wife, 2nd interview).

Another extremely valuable aspect of the service was the availability of a British Kidney Association Charity House near the hospital. This allowed participants, especially spousal donors and/or those who lived a considerable distance from the hospital, to stay closer together if they were discharged separately, which made visiting and supporting each other much easier.

Some donors, particularly those with unresolved questions or concerns, felt that there was a need for a dedicated transplant 'counsellor', or, at the very least, a dedicated health professional who was readily available to, formally or informally, answer their questions and provide them with information and support in a confidential environment:

"The hospital were fantastic but it's just the lack of.... The transplant coordinator said she's on the end of the phone if you've got a question or whatever, which I thought, oh great. Because when I said to my doctor could I have some sort of counselling she said, there's nothing. When I said that to the coordinator she said she should have put you onto me.... But I have found it difficult because if I want to ring her it's my day off and my day off is her day off. I don't expect her to be sat there on the end of the phone waiting to speak to you but I think it would be nice if there was something. Some other way or somebody else that you could make an appointment to go and see them.

It's not really counselling as such, it's just when questions come up it would be nice to have someone that you could ask. It's nothing really
specific, it just would be nice if there were somebody at the other end of the phone and you could ask if you thought of something.”
(D10, wife, 1st interview).

Many of these issues are key responsibilities of the live transplant co-ordinator. However, at the time of data collection, the transplant unit only employed one part-time live transplant co-ordinator. Consequently, many of these participants were aware of her role and most, if not all, had utilised her services at some point. However, they felt that her time was very limited and, therefore, they often felt that they could not spend as much time with her as they wished.

This situation has now changed somewhat. After data collection for the study, the transplant unit employed an additional full-time live transplant coordinator. However, the findings suggest that further professional emotional support is required, perhaps in the form of a dedicated counsellor or psychologist.

Counselling, in live transplantation, can be used effectively to explore issues such as the decision making process and feelings and concerns about transplantation, in an open, non-judgemental and confidential environment (Argles 1997, Hiller et al 1998, Eggeling 1999a, 1999b and Eggeling 2000). Having access to a specialist counsellor to discuss issues arising from live transplantation has been found to be beneficial and would, therefore, appear to support the services of a counsellor as an integral member of the transplant team (Eggeling 2000).

Many transplant units believe that behavioural and psychological health, as well as social support, are important aspects of a patient’s ability to recover from
surgery and cope with unforeseen difficulties; therefore, a psychosocial evaluation should be a mandatory requirement of the screening and selection of living organ donors (Olbrisch et al 2001). Consequently, many transplant units have now incorporated routine pre-transplant psychosocial assessments of prospective families into the routine comprehensive pre-transplant medical assessment process (Morris et al 1987, Argles 1997, Conrad and Murray 1999).

However, there is relatively little empirical evidence available that explores the value of routine pre-transplant psychological assessments, despite their routine use in some transplant units. There is, therefore, a need for further empirical evaluation to establish the potential benefits, or not, of such an intervention.

Whilst the transplant unit that was the setting for this study does employ a transplant psychologist, routine psychosocial assessments were not performed. Only 'problem families', referred by the transplant team, were psychologically assessed. Findings from the study suggest that, in future, the transplant unit should consider offering 'formal or informal' counselling to families who require or request it. Prospective families, however, also need to be aware of the availability of a specialist psychologist and what such a service could offer them. Consequently, the unit psychologist should, if possible, attend all future information evenings, to talk to families about the psychologist's role, and how they can access the service if they feel the need to.

Whilst R3 was generally happy with the emotional care and support that she received in hospital following her transplant rejection, she was very unhappy and
disappointed with the emotional support provided to her after discharge, particularly from the transplant psychologist and, to a lesser extent, the transplant coordinators.

R3 wanted professional emotional support from the transplant team and, given her state of mind at that time, particularly her suicidal feelings, and the fact that she had requested assistance, perhaps indicates that she probably could have benefited from psychological intervention. However, she felt that the way in which this support was initially offered to her (a message was left on her answer machine by the psychologist) was impersonal, unprofessional and uncaring. This left her feeling unable and unwilling to access the service and, despite further efforts to engage her (a follow up letter was sent by the psychologist and another telephone call was made whilst she was in OPD clinic), ‘bridges’ had perhaps been irretrievably ‘burnt’.

Whilst patients have to take some responsibility to request or to access services that are either available and/or are offered, the fact that R3 was offered psychological support that she wanted and had requested, but subsequently failed to access, has very important service implications. The transplant psychologist believed that, particularly in this situation, R3 needed to ‘opt in’ to psychological therapy, as forcing her to participate unwillingly would have increased the probability that she would either have not utilised the service properly or would have simply found it unhelpful and perhaps even counter-productive. However, such a service should be offered in an appropriate and meaningful way that
increases the likelihood that patients who request or require it, access and use it properly.

Unfortunately, there is very little research available that explores the psychological responses to graft failure (Streltzer et al 1983, Hudson and Hiott 1986) or the most appropriate method of providing care and support to such patients and their families. There is, therefore, undoubtedly a need for further empirical research in this area. I also felt that the transplant unit missed an important opportunity to learn more about these relatively rare occurrences, which could have subsequently been used to help aid service development and to help ensure that suitable care and support was provided to families in the future.

However, research has shown that a comprehensive multi-disciplinary team approach, involving all members of the transplant team, especially psychologists or counsellors, whereby patients are provided with the necessary support and suitable opportunities to discuss their feelings, can help to ensure that patients achieve resolution when their transplant fails (Streltzer et al 1983, Hudson and Hiott 1986). This support should be provided whilst in hospital, and especially after discharge when patients may also have to cope with readjustment to dialysis (Streltzer et al 1983). Perhaps a post graft failure psychological support protocol is required?

A small scale US study by Streltzer et al (1983) also found that patients who experienced a grief like reaction post graft failure generally felt ill-prepared for their transplant rejecting. Perhaps, therefore, routine pre-transplant psychological
assessments are also required, where issues such as graft rejection and possible coping mechanisms could be explored in more depth than information evenings allow. However, this research did not clarify if patients in the study had received such interventions before transplantation and no research is available that supports, or refutes, the use of pre-transplant psychological assessments in this way.

8.6 Two centre hospital care

Most families, especially those in South-West England, were cared for by two different hospitals; their local hospital and the regional transplant centre, which coordinated their treatment and care. Although this did not cause problems for some families, it did for most. Common problems included break downs in communication between centres (e.g., missing appointments and blood results), open disagreements over treatment (e.g., the necessity and timing of pre-emptive transplants) and, apparently, even offensive derision of other health professionals in front of some participants.

Participants generally found this to be confusing, unprofessional and often resulted in them doubting treatment plans, which caused uncertainty and anxiety:

"They've got a very different attitude and way of thinking up there compared to down here. I think down here were more thinking come to terms with dialysis and get well on dialysis and then consider transplantation and I've had to adapt to that way of thinking because when I realised that I was going to have at least 6 months on dialysis I thought well I've got to be positive about it.

But down in this part of the world they're slightly more conservative, cautious and... you always have to fight what comes as a matter of course up at the transplant centre. Down here people are more resigned to, oh well go on dialysis, transplantation is a big thing. They're a bit wary of it. So I feel we've gained a much more national perspective on it, which is
much more hopeful. Whereas the professionals that I’m dealing with down here are for some reason, maybe because they’re not actually working in that environment and don’t come into contact with it, sceptical about it. So we are having to push all the time and then you begin to wonder well is it right for me or are these people actually right in what they are saying? And when my doctor here says, some people just don’t want a transplant they will stay on dialysis, is he trying to tell me something and should I listen to him? Does he think something is going to go wrong? You begin to question yourself... but that is what they are like here.... Well it’s not the centre of where things are happening.

I think there has been very much confusion and there is definitely some professional rivalry between the two hospitals, which does in fact brush off on patients.... They resent having lost transplants down the road, I know that, and obviously it’s nice to have your own patients. I think there is a lot of power politics going on and when I think that human beings are being used as pawns in a power game it makes me incredibly angry.... On the other hand I do believe that everything is being done for my best possible care."

(R4, sister, 1st interview).

Specialist medical treatment in the UK, such as transplantation, is now generally only performed in dedicated regional centres of clinical excellence. It is probable, therefore, that patients who require kidney transplants and do not live near such centres will be co-managed by two different hospitals. Inevitably, the more clinicians involved in a patient’s medical care, the greater the likelihood for disagreements. However, open hostilities and discordance amongst health professionals, as found in this study, are clearly unprofessional and have a detrimental, unsettling effect on patients and their families. Health professionals should, therefore, always carefully consider their behaviour in the presence of patients.

8.7 Follow up care

Most donors were unhappy with their post-transplant follow up care and felt that it was inadequate, especially compared to that provided to recipients. Many
found this disconcerting and believed that their recovery, health and well being were not being monitored closely enough. Consequently, some donors felt ‘undervalued’ by the transplant team, and some even felt that they had been treated as ‘a means to an end’. Similar findings have been reported by Hilton and Starzomski (1994), Burnapp (1998), Eggeling (2000), Peters et al (2000) and Crombie and Franklin (2006).

Monitoring the effects of kidney donation on live donors is a responsibility and obligation of the transplant team (Jawad et al 2003), as it allows post-transplant problems to be promptly identified and treated accordingly (Hilton and Starzomski 1994). However, post-transplant follow up care also offers other important benefits, such as providing health professionals with an opportunity to gather crucial longitudinal, clinical outcome data, which could subsequently be used to help inform and develop future clinical practice (Olbrisch et al 2001).

But how frequently and for how long should donors, particularly those who have had uneventful recoveries, be routinely followed up after transplantation? The Amsterdam Forum (2004), an international committee of transplant experts who developed international standards of care for live kidney donors, recommends that:

‘After kidney transplantation the transplant centre is responsible for overseeing and monitoring the post-operative recovery process of the donor until that individual is stable, including the provision of care for morbidity that is a direct consequence of donor nephrectomy’. (p. 492).

However, no specific guidelines on the timescale or frequency of donor follow up care are offered. Consequently, it would appear that this is left to the
discretion of each transplant unit, based largely on individual donor’s post-transplant recovery. All participants who had experienced post operative problems were being followed up far more frequently, and some had also received further treatment (e.g., laparotomies for wound problems), than participants who had made ‘normal’ recoveries. Donors who made normal recoveries were generally seen within 4-6 months post transplant and then, if their condition was satisfactory, they were scheduled to be seen annually.

Perhaps donors’ (particularly spousal) perception that their follow up care was inadequate was exacerbated by the recipients’ rigorous and frequent post-transplant follow up care. Nonetheless, whatever the reasons for these feelings, the fact that they exist, and have also been reported in other national and international studies dating back over a decade, is an indication that follow up care for live kidney donors needs to be addressed (Hilton and Starzomski 1994, Burnapp 1998, Eggeling 1999a, 1999b, 2000).

However, if current routine follow up care for live kidney donors who have not experienced any significant post-transplant complications is sufficient, then perhaps all that is required in future is for health professionals to carefully explain to donors what they can and should reasonably expect from their post transplant follow up care, particularly in comparison to recipients. Donors should also be encouraged, as they generally are, to visit their GP if they feel unwell at any time after discharge.
Donors were often unsure how follow up care should improve or what they really wanted from it, but all felt that it should be better. However, as this and other studies have found, as some donors often feel undervalued post-transplant, some transplant units are now looking at ways to improve this situation. Eggeling (2000) reports that, in an endeavour to address donors’ feelings of being undervalued and forgotten post transplantation, her transplant unit held a tea party to which all donors, their families and recipients were invited – it was well attended and feedback received was positive.

8.8 Conclusion

Participants’ positive comments about the transplant service were generally encouraging and demonstrate a high quality of service provision. However, there can be little doubt that the live transplantation process could be further improved (Peters et al 2000). In particular, attention should be paid to areas, such as donor follow up care, information provision and two centre care, where participants felt that quality of care should be improved. In the interests of service development, this study demonstrates the importance of involving service users in the empirical evaluation of service provision.

This chapter has presented an evaluation of transplant service provision from the perspective of live kidney donors and recipients. In the next chapter, the analysis of key study findings are discussed.
CHAPTER NINE: Analysis of key findings

9.1 Introduction
In the previous chapter, participants’ experiences of service provision throughout the live transplantation process were discussed. In this chapter, some of the other key findings that emerged from the data are discussed; these include, the effects of being diagnosed with a chronic renal condition, methods of coping pre and post transplant, the impact of irreversible graft rejection and participants’ experiences of participating in research interviews.

9.2 Discovery, diagnosis and grief
The initial diagnosis of renal failure caused a grief like reaction in all recipients and often their close families. This emotional response was analogous to grieving behaviour described by Kubler-Ross (1970) in her seminal work on death and dying. As with the terminally ill, recipients experienced a grieving process prior to transplantation. All recipients initially felt shocked and incredulous when they were first informed of their condition and the necessity for dialysis and/or a kidney transplant:

“I was diagnosed as having poly-cystic disease 12 years ago but nobody really took much notice after the initial diagnosis. I just went off and carried on with the rest of my life and as far as I was concerned, that was it really. Although I’m a medical professional I never really looked into it, because nobody really explained to me that I should. Eventually, about 6 or 7 years ago, I had an episode of abdominal pain and went to my GP who referred me to a GI consultant, who thought I should be seen by a nephrologist. It was him that said to me, you do realise that your renal function is going off and you’re going to have to have a kidney transplant or go on dialysis in due course? At the time it came as an absolutely appalling shock. I was devastated really.”
(R3, wife, 1st interview).
These feelings eventually changed to anger and denial, particularly if they felt reasonably healthy at the time:

"My doctor said you’ll probably end wanting a transplant, which did rock the boat a little bit. I came to terms with it quickly I think, but I did have a couple of weeks of just thinking about it. Then I went into denial...thinking no... because you still feel fit and healthy. I thought this isn’t going to happen to me."

(R7, husband, 1st interview).

Grief, as an emotional reaction, is fairly common in patients with ESRD and has been reported nationally and internationally (Davies 1975, Baines and Jindal 2002). This phenomenon has also been found in other chronic conditions, such as diabetes and ischemic heart disease (Bowlby 1980, Kleinman 1988, Vickers 2001). Chronic illness can also have a profound affect on family members and, consequently, grief is often not exclusively confined to sufferers (Byng-Hall 1997, White and Grenyer 1999, Lowes et al 2005).

This was certainly the case in this study, as often close family members, particularly spouses and parents, also experienced (or were reported by participants to have experienced) similar, although often lesser, reactions to the recipients. But what is grief? Why does it occur in chronic conditions? What affects can it have on patients and their families? And how can resolution be achieved?

Grief is a form of unbearable sadness (Baines and Jindal 2002) and is, essentially:

‘An emotion that draws us toward something or someone that is missing. It arises from an awareness of a discrepancy between the world that is and the world that should be’ (Parkes 2000, p326).
Patients are often diagnosed when they are fit and well and often with little or no warning or symptoms that they are ill (Davies 1975). All recipients in this study, except R11, were initially diagnosed when they felt reasonably healthy. R11 had only felt ill for a relatively short period of time and his lack of major symptoms made him think that he probably only had flu. It is not surprising, therefore, that patients often find it difficult to accept, or even believe, that they have a serious illness and the prospect of dialysis and/or a kidney transplant can also be overwhelming (Davies 1975) and, thus, exacerbate the situation.

Grieving is, therefore, a necessary and common coping mechanism utilised by individuals as a means of coming to terms with the variety of physical and psychosocial aspects of life that may be affected (Hansen 1972, Vickers 2001). For example, due to their illness, many patients may experience loss of health, control of one’s life, employment (and the consequent financial implications), independence, a ‘normal’ lifestyle and expectations for the future, as well as potential relationship problems (Davies 1975, Kleinman 1988, Wilson 1995, Altschuler 1997, Vickers 2001).

All recipients were, to a varying degree, affected in this way, which often led to many, and often their families, having to make considerable lifestyle changes. It would appear, therefore, that participants were simply grieving for the life and health that they had apparently lost and also for the potential loss of their ‘imagined future’. Grief, and denial in particular, should therefore be viewed as a normal reaction and an effective coping mechanism for mediating the impact of ESRD (Long 1995, White and Grenyer 1999).
Whilst the extent and severity varied, most participants (primarily recipients) had, at some stage, felt depressed as a consequence of their grief and the inevitable effects of ESRD. Such feelings, along with anger, sadness and anxiety are relatively common (Christensen et al 1989). Reported rates of clinical depression vary and are often confused with the symptoms of uraemia (high blood urea levels), which are almost identical, but can be as high as 53% and some instances of suicide have also been reported (Davies 1975, Smith et al 1985, Long 1995, Christensen and Ehlers 2002).

Generally, though, the more that life is disrupted, particularly if dialysis is required, the greater the likelihood for depression (Long 1995, Christensen and Ehlers 2002). This was certainly the case for recipients, such as R4, in this study whose lives were profoundly affected by ESRD. The effects on family members can also be significant, especially if they have to adopt the role of carer (Long 1995).

All participants had achieved resolution from their grief and attained a stage of acceptance before they participated in the pre-transplant interviews. The ability to adjust often depends on a variety of factors including past experience, personal traits, social support and treatment modalities (Vickers 2001). However, this transition had predominantly occurred when the recipients’ physical health had begun to noticeably deteriorate. It was only at this stage that they could properly consider and accept the need for a renal transplant.
These findings have important clinical implications. For example, health professionals should recognise that grief-like reactions, particularly feelings of shock, denial, anger (including hostility) and depression are normal reactions in those affected by ESRD. The initial diagnosis and any subsequent prognosis and treatment discussions should, therefore, be handled in a careful and empathetic manner. If possible, it may also be wise to have a friend or family member present when delivering this information, so that they can support the patient (Byng-Hall 1997).

Nurses and other appropriate health professionals need to provide patients and their families with an understandable rationale for feelings of loss, grief and fear, and give them permission to grieve and reassurance that grief is both normal and acceptable (Lowes et al 2005). Patients should also be encouraged to retain some degree of hope and optimism (Davies 1975, Altschuler 1997), providing, of course, that it is appropriate and realistic to do so. Throughout the pre-transplant interviews, the prospective transplant was a considerable source of hope and optimism for all participants; offering them the potential for a better and perhaps even ‘normal’ life.

Patients and their families should be provided with understandable verbal and written information and encouraged to ask questions as and when appropriate. Health professionals should also encourage patients and their families to talk about their feelings. Consequently, support for and from other family members is extremely important (Byng-Hall 1997, White and Greyner 1999, Christensen and Ehlers 2002). Most importantly, however, is that, if clinically possibly, patients
should have adequate time and support to adjust to their condition and to accept
the eventual need for dialysis and/or a kidney transplant. However, in some
extreme cases, some patients may require professional emotional support and
assistance to help them achieve resolution (Christensen and Ehlers 2002).

Some recipients may also become depressed after transplantation, even if they
make good clinical recoveries and return to satisfactory physical health. Based on
clinical experience and case study evidence in Scotland, UK, Baines and Jindal
(2002) suggest that this occurs because they grieve for the 'loss of their imagined
past'. That is, the life that they might have had if they had not developed renal
failure. However, this did not occur in any recipients in this study who made
normal recoveries.

9.3 Pre and post transplant coping mechanisms

ESRD, dialysis and/or transplantation impose a variety of stressors on patients
and their families that require adaptation. Understanding how families are
affected by, and cope with, these issues is essential, as it can help to inform and
develop clinical practice, thus ensuring that optimal care and support is provided
to patients and their families (Voepel-Lewis et al 1990, Flaherty and O’Brien

However, this area has been subject to relatively little research (Lindqvist et al
2004) and, although some studies have explored stressors and coping styles
associated with ESRD (e.g., Devins et al 1986, Flaherty and O’Brien 1992),
dialysis (e.g., White and Greyner 1999) or transplantation (e.g., Sutton and
Murphy 1989, Voepel-Lewis et al 1990, White et al 1990, Frazier et al 1995, Christensen and Ehlers 2002, Lindqvist et al 2004), they have only focused on these specific periods in the illness/treatment trajectory. It is therefore unclear whether stressors or coping styles change over time (Sutton and Murphy 1989, White et al 1990).

This study, because of its longitudinal nature, was therefore quite unique, as it focused on donor and recipient perspectives, pre and post transplant. The data show that many stressors do change over time, with the progression of illness and treatment and, consequently, so too do coping mechanisms.

The main stressors for participants were associated with ESRD and, where appropriate, dialysis, the impending transplant (e.g., the operation and whether the transplant would be successful) and life after transplantation (i.e., the fear of graft rejection/failure). As the illness and transplantation process produced a variety of different stressors, participants utilised a variety of different coping mechanisms. However, to understand how they coped and adapted to these stressors, it is first imperative to explore what coping is and what purpose(s) it serves.

Coping is a process of adapting to adversity and involves:

‘Constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person’ (Lazarus and Folkman 1984, p141).
Coping can help in adjusting to chronic illness, solving problems and reducing stress (Hudson and Hiott 1986). However, the process essentially serves two fundamental functions; managing or altering the problem with the environment causing distress (referred to as 'problem-focused coping') and regulating the emotional response to the problem (referred to as 'emotion focused coping') (Lazarus and Folkman 1984).

Problem and emotion focused methods of coping are the two main styles of coping. Problem focused coping involves taking appropriate action to deal with a stressful event (Watts and Brooks 1997). For example, seeking information about an issue of concern before making an informed decision about the situation one is faced with. Problem focused coping is more likely to occur when stressors are appraised as amenable to change (Lazarus and Folkman 1984).

Conversely, emotion focused mechanisms involve lessening emotional distress and includes strategies such as denial, avoidance, minimisation, distancing, selective attention and seeking positive values from negative events (Lazarus and Folkman 1984). This approach may involve altering the way in which a situation is interpreted without actually changing the situation (Watts and Brooks 1997). For example, looking on the 'bright side' or trying not to think or worry too much about actual or potential problems. This approach is more likely to be utilised in situations that individuals feel they have little or no control over. This style of coping is:

'Designed to make life more bearable by avoiding realities which might prove to be overwhelming if directly confronted' (Goldstein 1980, p90).
Emotion and problem focused coping strategies can be utilised independently or concurrently (Lazarus and Folkman 1984). Neither is necessarily superior to the other and which, or whether both are used often depends on the person, the situation and the physical and psychosocial resources available to them. Ultimately, the efficiency and appropriateness of a strategy is determined only by its effects in a given encounter and its effects in the long term (Lazarus and Folkman 1984). However, while emotion focused strategies can be highly effective at managing particular stressors, their use in certain circumstances can be inappropriate and potentially harmful. For example, if a person utilises denial or avoidance techniques and, as a result, fails to seek or adhere to medical advice or treatment; e.g., deliberately ignoring the presence of a breast lump.

Participants in this study utilised both styles of coping at various stages, depending on the stressors. However, what was common to all participants was how they coped with the illness and transplantation process as a whole. All focused on, and coped with, problems as and when they occurred, rather than attempting to consider and cope with the whole process simultaneously, including possible future problems. If patients feel overwhelmed with their situation, it is normal for them to break the process down into ‘smaller, more manageable chunks’ (Lazarus and Folkman 1984). Patients, particularly those who feel beleaguered by the transplantation process, should therefore be encouraged to consider coping with the process in stages, rather than trying to cope with the process as a whole.
ESRD is known to cause a variety of physical and psychosocial problems, such as fatigue, depression, lifestyle changes and social isolation (Devins et al 1986, Long 1995, White and Grenyer 1999, Christensen and Ehlers 2002). The effects of these stressors are also often mediated by other factors, such the extent and severity of the illness, treatment requirements (particularly dialysis), time spent on dialysis (if appropriate) and the ability to cope and adjust (Long 1995). The lives of all recipients, especially those on dialysis, were affected, to varying degrees, in this way. However, research has shown that most patients are able to adapt effectively to these stressors and integrate their illness and its treatment into their lives in a way that does not harm their wellbeing (Devins et al 1986).

A common emotion focused coping mechanism used by most recipients to deal with these stressors, particularly if they were significantly debilitated, was to ‘reduce their expectations’. This essentially involved trying not to dwell on things that they could no longer do because of their condition (e.g., swimming or going on holidays) but to seek enjoyment from other, less physically demanding activities, such as reading or listening to music. This style of coping can be very effective in chronic illness as it can help to minimise feelings of hopelessness and depression and promote emotional adjustment (Altschuler 1997).

However, the most significant pre-transplant coping mechanism used by all participants, especially recipients, was hope and optimism for a better life after the transplant. A successful kidney transplant is often viewed by recipients as offering them salvation from ESRD and a return to a normal lifestyle (Hudson and Hiott 1986, Schweitzer et al 2003, Lindqvist et al 2004).
However, if expectations of the transplant are unrealistically high, particularly if potential post-transplant complications are not properly acknowledged, it can result in distress and depression if these expectations fail to materialise (Schweitzer et al. 2003). Health professionals therefore have an extremely important role to play, particularly during the pre-transplant work-up process, in encouraging donors and recipients to think realistically about the prospective transplant in a way that does not harm their hopes. Consequently, it is essential that any information provided is balanced, accurate and understandable.

Despite the prospective transplant being a significant source of hope and optimism, it was also a considerable stressor for all participants. Common concerns were largely the same amongst donors and recipients and included fear of the operation, post-operative pain, concern for each other’s health and, notably, would the transplant be successful? These concerns have also been reported in other studies (e.g., White et al. (1990), Burroughs et al. (2003) and Schweitzer et al. (2003)) and, if not addressed, can create anxiety and uncertainty in donors and recipients (Hiller et al. 1998).

Participants dealt with these concerns using problem and emotion focused styles of coping. Concerns about the procedure were dealt with by seeking information. This is a positive problem focused coping strategy and, by trying to find out what is likely to happen to them, patients are more likely to be better prepared for surgery and the post-operative experience, more in control of the situation and, consequently, less anxious about the impending procedure (Callaghan et al. 1998,
Information that informs patients that distressing feelings can be moderated, or even prevented, allows the event to be reappraised as less threatening (Watts and Brooks 1997).

Health professionals should, therefore, ensure that donors and recipients are well informed and supported throughout the transplantation process and have sufficient opportunities to speak to them about their fears and concerns (Burroughs et al 2003). Where appropriate, donors and recipients should also be encouraged to talk to each other about the transplant so that they can reassure each other that they are happy to proceed with the transplant, despite the risks.

However, before, and particularly after, transplantation, the biggest stressor for all participants, especially recipients, was the fear that the transplant would not be successful. The fear of rejection or failure of the transplanted kidney (and the subsequent need for dialysis) is the most common concern in patients and their families (Hudson and Hiott 1986, Sutton and Murphy 1989, White et al 1990, Frazier et al 1995, Lindqvist et al 2004). Anxiety is also often further exacerbated during follow up clinic visits, after blood tests or if recipients feel unwell, particularly if they have any physical signs that resemble rejection (Hudson and Hiott 1986).

This persistent fear was most acute in the first few months after transplantation, causing feelings of uncertainty and anxiety that affected the ability of all participants, especially recipients and spousal donors, to plan ahead. Due to the lack of longitudinal data, it is unclear how long these feelings persist. However, a
small scale Swedish study by Lindqvist et al (2004) found that, in 30 kidney transplant recipients, the fear of rejection was still the most significant stressor 4 years post-transplant.

In this study, the fear of rejection had diminished somewhat after 10 months. Consequently, participants felt more in control of their lives and more able to make short to medium term plans for the future (e.g. going on holidays). However, as participants recognised that the success or failure of the transplant was, essentially, beyond their control, they utilised emotion focused styles of coping to deal with this particular stressor. This involved acknowledging the reality of rejection, but not dwelling on it and ‘making the most out of life’:

"We are aware things could go wrong. You have it in the back of your mind, so you're not too shocked if it happens... but we believe it will be ok. It can reject and you have to be ready for it, but it is absolutely no good worrying about it. If anything happens then you deal. You know, it's there in the background and you deal with it if it happens, but we don't worry about rejection, I think that's a waste of time. I think you just have to try and make the most of it."

(R1, wife, 2nd interview).

In a German study by Schweitzer et al (2003), 67 live donor-recipient couples were interviewed between 1996 and 2002 and the authors found that this type of coping mechanism, which they refer to as ‘optimistic fatalism’, was the most common coping mechanism utilised by participants to deal with the prospect of failure. Participants acknowledged the reality of potential complications such as rejection, but dealt with them in an emotionally neutral fashion and did not wish to deal with them in more detail (Schweitzer et al 2003).
Coping strategies such as ignoring uncertainties, living day to day, psychological distancing, avoiding the threat and denying its implications are common in situations that cannot be personally mediated or controlled and serve a valuable psychological purpose (Lazarus and Folkman 1984). In this study, this approach helped to decrease stress and anxiety associated with the fear of rejection and allowed participants to get on with their lives.

This style of coping, if used appropriately, is useful and can help to sustain morale and alleviate distress and is not necessarily harmful, providing that those who use it do not ignore reality (Lazarus and Folkman 1984). However, due to the lack of research in this area, it is unclear whether this style of coping has any psychological repercussions for recipients whose transplants reject or fail. That is, is the rejection experience even more devastating for recipients, like R3, because they have not previously seriously considered the possibility of rejection, or how they would subsequently deal with it? It is therefore imperative that more research is conducted into pre-transplant coping mechanisms, particularly where transplants are subsequently unsuccessful.

Fortunately, all participants were able to adapt to and cope with the demands of illness and treatment. Nonetheless, nurses and other health professionals have an important role to play in caring for, informing and supporting patients and their families throughout the transplantation process. Donors and recipients should also be encouraged to discuss any worries or concerns that they have about transplantation with health professionals (Voepel-Lewis et al 1990, White et al 1990). Social support from family and friends is also important in the facilitation
of coping and emotional readjustment (Hudson and Hiott 1986, Flaherty and O’Brien 1992, Frazier et al 1995, Long 1995, White and Grenyer 1999, Schweitzer et al 2003). However, as family members often experience similar stressors to patients it is also important that they too are provided with help and support (Voepel-Lewis et al 1990, Frazier et al 1995).

Being positive, optimistic and making the most out of life is a relatively common coping mechanism in transplant recipients (White et al 1990, White and Grenyer 1999, Lindqvist et al 2004). Therefore, although recipients should be encouraged to think realistically about their transplant and take care of their general health, they should be encouraged to make the most out of their lives as kidney transplants, even from live donors, do not last forever. All transplant patients, particularly those with significant emotional problems, should have access to and support from a clinical psychologist. Further research is also required into the potential benefits of routine pre-transplant psychological assessments. For example, such encounters could be used to explore coping strategies and to encourage patients to think realistically about the transplant, in a way that does not significantly harm their hopes (Hiller et al 1998, Calder and Chang 2004).

9.4 ‘Loss of imaginary future’: Grieving the loss of a transplanted kidney

Live kidney transplantation is a highly successful procedure that carries an average one year graft survival rate in the UK of 93% (UK Transplant 2006f). Unfortunately, whilst rare, irreversible graft rejection is inevitable in a small proportion of recipients. The physical and psychosocial trauma of transplant rejection/failure, the subsequent necessity for dialysis and the ability of patients
and their families to cope and adjust to the experience is of considerable concern to health professionals (Streltzer et al 1983, Hudson and Hiott 1986).

However, the experience of graft rejection, from the patient’s perspective, has been subject to very little research. Despite an extensive literature review, only several empirical studies could be found that specifically explored the personal dimensions of graft rejection. This lack of research significantly limits the insight and understanding of the rejection experience that could also be used to inform and develop clinical practice.

The impact of graft rejection is profound and often induces feelings of grief and loss (Streltzer et al 1983, Hudson and Hiott 1986, Baines and Jindal 2002, Olbrisch et al 2002). Consequently, as the data show, patients and their families often experience emotions such as anger, sadness, depression and, in some instances, suicidal feelings (Carosella 1984, Hudson and Hiott 1986, Christensen et al 1989, Baines and Jindal 2002, Lindqvist et al 2004). Streltzer et al (1983) explored the emotional reactions to graft failure in 25 kidney transplant recipients, over 10 years, in the USA. Most experienced feelings of grief following the loss of their transplant. However, some experienced no or minimal grief and depression and the authors refer to these as ‘deniers’. These recipients essentially used denial as a coping mechanism to help them deal with their loss and minimise their feelings of sorrow and despair (Streltzer et al 1983).

A variety of other factors can also exacerbate the rejection experience. In the case of R3, for example, this included problems associated with graft rejection
and dialysis, such as anaemia, lethargy, body image issues and temporary relationship problems, caused by role change and increased dependency. Live transplant recipients also often have to contend with feelings of guilt for having seemingly put their donor through a major surgical procedure unnecessarily (Schweitzer et al 2003).

However, a significant contributory factor in this study appeared to be due to the fact that R3 had not properly considered or anticipated the prospect of graft rejection. She felt that this was primarily because she had not been properly prepared for rejection by the transplant team, despite being informed of the possibility. In Streltzer et al’s (1983) study, ‘deniers’ reported feeling better prepared for rejection than ‘grievers’. Therefore, perhaps preparedness is related to the way in which recipients deal with the prospect of rejection before transplantation.

In the pre-transplant interviews, all recipients, including R3, used emotion focused coping mechanisms, such as avoidance and denial, to deal with the prospect of rejection. If used appropriately this can be a useful coping mechanism that helps to minimise stress and anxiety (Lazarus and Folkman 1984). However, the use of such coping styles perhaps exacerbates the emotional impact of rejection because recipients, such as R3, have not properly anticipated rejection or considered how they would cope with it, if and when it actually occurs (Salmons 1980, Carosella 1984, Schweitzer et al 2003).
Finally, another related factor was the subsequent necessity for dialysis, which R3 had not expected or wanted. Such unanticipated, uncontrollable and undesirable events following rejection, particularly if problematic, can compromise a patient’s sense of control, causing feelings of helplessness and hopelessness, which can further compound depression (Carosella 1984, Christensen et al 1989, Christensen and Ehlers 2002). As many live transplants, including R3’s, are now performed pre-emptively, many recipients undergo transplantation with little or no experience of dialysis. Consequently, they have not learnt how to cope with dialysis or how to incorporate the demanding regime into their lives. This, coupled with unanticipated rejection, would appear to significantly compound depression and also serve as a constant reminder of an unsuccessful transplant:

“This think my wife’s outcome was not having to do anything – no haemo, no CAPD, just successful and when it wasn’t she began..... I mean going to dialysis, apart from the fact that it made her feel shit, was a constant reinforcement that she was sick and she didn’t want that. The CAPD she doesn’t have to go with other sick people...... but all the paraphernalia upstairs reminds her that she does need that treatment.”

(D3, husband, 2nd interview).

Baines and Jindal (2002) formulated the theory of ‘loss of the imagined past’ to help account for the feelings of grief and loss that some transplant recipients experience following a successful kidney transplant. They propose that some recipients grieve for the period in their lives, before transplantation, that they lost because of their ill health. However, in the case of R3 it would appear that the converse is true; that is, following the rejection of her transplanted kidney, she grieved for ‘the loss of her imagined future’.
Some recipients of unsuccessful transplants are often preoccupied with their loss and its implications for their future (Streltzer et al 1983). Similarly, many chronic illness sufferers also often come to realise that ill health will probably affect their lifestyles and result in the loss of life choices, including plans for the future (Vickers 2001). The data in this study would suggest that after the failure of her kidney transplant, R3 lost her hopes, dreams and expectations for the future. It is therefore proposed that this loss was the source of her grief and depression:

"I think the professor was right when he said to me, you are going through a grieving process because you are not the person that you were and you are not the person that you thought you were going to be. So you are grieving for the person that you’ve lost and the lost opportunity."

(R3, wife, final interview).

Live donors, particularly spousal, are also often profoundly affected by graft rejection, as they also have a vested interest in the transplant, the recipient’s health and well being and, as in the case of D3, often play an important role in supporting the recipient through the process. Consequently, they frequently experience similar emotional reactions, such as anger, disappointment, sadness, regret, guilt, grief and, occasionally, even suicidal thoughts (Nolan 1999, Fox and Swazey 2002, Olbrisch et al 2002, Schweitzer et al 2003).

Weizer et al (1989) reports of two cases of suicide in genetically related kidney donors in Israel following graft rejection and the subsequent death of the recipients. Schover et al (1997) explored the experiences of 167 live kidney donors in Ohio, USA, 39 of whom were involved in unsuccessful transplants. Most came to terms with the loss and did not express guilt or bitterness but many believed that their role as donor made the failure more devastating and 4 experienced suicidal feelings (Schover et al 1997). Unfortunately, there is,
perhaps, a tendency for health professionals to forget about donors and the effect that rejection can have on them, as recipients, understandably, are generally the focus of attention.

Fortunately, depression associated with graft rejection is usually short lived and generally improves as physical health improves (Salmons 1980, Streltzer et al 1983). For R3, this was a pivotal moment in her physical and psychological recovery and helped to promote the feeling of regaining personal control of her life. Consequently, most patients are eventually able to cope and adjust to the experience (Carosella 1984). However, given the suicidal feelings experienced by R3 and some recipients in other studies (e.g., Klein et al 1984, Streltzer et al 1984), suicide in some recipients and/or donors will always be a possibility because of the trauma of graft rejection.

Nurses and other health professionals therefore have an extremely important role to play in caring for and supporting recipients, donors and their families through the rejection experience and facilitating their emotional adjustment. Where appropriate, support should continue after discharge home, if rejection occurred in hospital, as this is when R3 felt most depressed and in need of support from the transplant team. Support from family and friends is also essential in helping patients adjust to their loss (Hudson and Hiott 1986):

"I could quite easily see how if I hadn't been lucky enough to have the love and support of my family and a particularly caring consultant... I would have topped myself."
(R3, wife, final interview).
Patients should be provided with sufficient opportunities to discuss their feelings and concerns with health professionals in an open and honest manner (Hudson and Hiott 1986). They should also be reassured that their feelings, such as grief and anger, are normal emotional reactions to rejection and, therefore, are to be expected (Carosella 1984). In helping patients understand and cope with the rejection experience, they should also be provided with understandable information about the process, prognosis and treatment options and encouraged to ask questions, as and when appropriate:

"They went out of their way to talk us through everything because they wanted us to know precisely what they were doing and what they were learning. I just wanted to know why it hadn't worked so I could understand it. They were very honest and I said what I'm interested in now is, is there anything that can be learnt that will help others and is what we've been through going to help or hinder our chance of getting another transplant"?

(D3, husband, 2nd interview).

Patients should also be encouraged to consider using appropriate coping mechanisms to make the experience more bearable, such as, hope (i.e., that things will get better) and initially taking things one day at a time (Streltzer et al 1983). They should also be informed that emotional turmoil, with no initial discernable method of coping, is normal; as the early stages of traumatic experiences are often spent acting and reacting to the situation and considering what has happened, before appropriate coping mechanisms can be identified and utilised (Lazarus and Folkman 1984). Patients should also be advised that emotional readjustment is possible and that most recipients of transplant rejections are able to cope with and adjust to the experience (Carosella 1984).
The prospect of another kidney transplant is often a source of significant hope and optimism for many recipients and they should, therefore, be informed that an unsuccessful transplant does not necessarily preclude the possibility of further transplants (Carosella 1984, Hudson and Hiott 1986, Fox and Swazey 2002). However, coming to terms with rejection and contemplating another transplant, with the associated risks, may take considerable time. Therefore, wherever possible, patients should not be rushed into making decisions about future treatment options and should be encouraged to discuss their hopes and fears.

Group therapy with other dialysis patients, some of whom may have also experienced unsuccessful transplants, may also be helpful for some recipients, particularly those with no previous experience of dialysis (Long 1995, Anonymous 2002). However, as with all interventions, group therapy may not be for everybody. For example, R3 felt that ‘reliving traumatic experiences’ in a group environment would be unhelpful and counter-productive. This belief should, of course, be respected, but such therapy, where available, should be offered, along with an explanation of its potential benefits.

However, patients who are struggling to accept, cope or adjust to graft rejection, particularly if they are having suicidal thoughts, may require professional psychological and/or psychiatric intervention (Carosella 1984, Streltzer et al 1984, Hudson and Hiott 1986, Christensen et al 1989). If required, such support should be offered in a considerate way that increases the likelihood that those who want it actually access it (Lazarus and Folkman 1984).
Besides providing care and support after rejection, patients and their families must also be properly prepared for transplantation and made fully aware of potential complications, such as graft rejection (Lumsdaine 2000, The Amsterdam Form 2004). Health professionals should therefore provide prospective families with balanced and understandable information and should encourage open and honest discussions about hopes, expectations and concerns (Burroughs et al 2003, Stothers et al 2005). However, whether information alone can properly prepare patients for the possibility of rejection is perhaps questionable.

Whilst further research is required to evaluate effectiveness and usefulness, routine pre-transplant psychological assessments would seem to be particularly appropriate (Olbrisch et al 2001. Such assessments could be used to establish what transplants mean to patients, to encourage realism and to explore worst case scenarios and potential coping mechanisms (Carosella 1984, Hiller et al 1998, Calder and Chang 2004). Asking prospective families to confront such issues may increase their anxiety levels and, given the distress commonly associated with rejection, perhaps would still not fully prepare them for the reality of rejection. However, interventions aimed at promoting reality, informed decision making and potentially moderating the rejection experience, if and when it occurs, is surely prudent.

However, further empirical research, particularly of a longitudinal nature, is undoubtedly required in this area, so that the rejection experience can be better
understood. The improved insight could subsequently be used to help support patients and their families through what is clearly a traumatic experience.

9.5 The interview experience

Non-maleficence is a fundamental ethical principle of all research involving humans. This means that researchers have a responsibility to ensure that their research does not harm participants or expose them to any physical or emotional risks (Holloway and Walker 2000). However, qualitative interviews do have the potential to provoke a multitude of feelings and emotions (Kvale 1996, Whittaker 1998), some of which can be potentially distressing. Consequently, exploring respondents' perceptions of participating in a series on research interviews about emotive and potentially distressing issues is imperative.

Due to the emotional nature of the study and the fact that some participants had become upset while being interviewed, I found it reassuring that no one regretted taking part in the research and that all families, especially family 3, had found the process helpful. This unexpected finding would, perhaps, suggest that research interviews do not necessarily cause distress, but are a medium through which participants can express their distress (Lowes and Gill 2006).

Other studies have also found that in-depth research interviews, although not purposefully therapeutic, can have a 'cathartic' or 'pseudo-therapeutic' effect on participants (e.g. Gale 1992, Measor and Sikes 1992, Sparkes 1994, Hatton et al 1995, James and Whittaker 1998, Aylott 2002, Morecroft et al 2004, Colbourne and Sque 2005). As depth interviews allow participants to talk openly about their
feelings, concerns and experiences, catharsis is, to some extent, probably
unavoidable, as being listened to by an interested listener can make an interview
a positive experience for participants (Kvale 1996). Perhaps, then, as all
participants found talking about their experiences helpful, the data may also
suggest that families may have also found talking to a counsellor before
transplantation helpful, as many had requested.

Repeated interviews with the same researcher may also significantly improve
trust and rapport between interviewer and interviewee, thus promoting the
development of a ‘quasi-therapeutic’ relationship. However, while research and
therapeutic interviews may have many similarities, the purpose of each is
fundamentally different. The main purpose of the research interview is to listen
attentively to what participants have to say, in order to acquire knowledge and
develop a greater understanding of their experiences, feelings and beliefs (Kvale
1996). It is not to intentionally offer any form of therapeutic help, advice or
counselling (although many may find the interview experience cathartic or quasi-
therapeutic), for which many interviewers have neither the training nor the time
(Kvale 1996).

Furthermore, as Kvale suggests, when patients request therapy, they do so with a
view to making fundamental changes in the way they understand themselves and
their world. In a research interview, they have not actively sought to instigate
new self-interpretations or emotional changes, but are invited by the researcher to
participate in the study (Lowes and Gill 2006).
Therefore, even if participants find the interview experience cathartic or 'pseudo-therapeutic', qualitative researchers must be aware of and respect the boundaries between research and formal therapeutic interviews. However, researchers who are involved in potentially 'emotive research' should also carefully consider the necessity for and access to professional emotional support for participants (and perhaps also for researchers themselves) who may require or request it. This was something that I carefully considered when planning this study. Consequently, I negotiated (anonymous and confidential) access to and support from the British Organ Donor Society (a support group) and a practising nephrology and transplant clinical psychologist for participants who required or requested support. To my knowledge, no one took up these options.

Nonetheless, far from being the potentially one sided affair that researchers often think research interviews are, these findings would suggest that:

‘Providing a non-judgemental and confidential environment, where participants can talk about their experiences in an open and unhurried manner with someone who is genuinely interested in what they have to say, can be of mutual benefit to researchers and participants’ (Lowes and Gill 2006).

9.6 Conclusion

This chapter has explored several key study findings, including grief associated with diagnosis, coping mechanisms, the impact of transplant rejection and the interview experience. This chapter demonstrates how challenging ESRD and live transplantation, particularly in the event of rejection, can be for donors and recipients. Continued empirical research is therefore required to help establish a foundation of knowledge that practitioners can utilise to adequately care for and
support patients and their families through the transplantation experience (Christensen et al 1989).

In the next chapter, the concept of gifting is explored in relation to the live transplantation process.
CHAPTER TEN: The gift exchange theory in live kidney transplantation

10.1 Introduction

In the previous chapter, the analysis of key study findings were discussed. In this chapter, data are interpreted within the framework of the theory of gift exchange. The theory of gift exchange was explored in chapter one and its potential relevance to health care, particularly live kidney transplantation, was discussed in chapter two.

However, to briefly recap, gift exchange is structured by a triple set of norms; giving, receiving and repaying, which Mauss (1990) defines as 'symmetrical and reciprocal'. This means that under certain socio-cultural circumstances, a person is supposed to offer a gift to a particular person. The person who is offered the gift is subsequently expected to accept it. The receiver is then under moral and psychosocial pressure to eventually 'balance out' the exchange by giving the giver something of equivalent worth. Failure to live up to any of these entwined expectations can produce disequilibrium and social strain that can affect the giver, receiver and those close to them (Fox and Swazey 2002).

It has frequently been postulated that organ transplantation is analogous with gifting, as the process has the fundamental dynamics of gift exchange and involves giving, receiving and, arguably, a form of reciprocation (Hilton and Starzomski 1994, Sque and Payne 1994, Conrad and Murray 1999). Some theoretical, anecdotal and clinical evidence suggests that gifting may, therefore, provide a useful framework for understanding the transplantation process, from the perspectives of donors and recipients. In particular, it could provide an
insight into factors that influence giving and receiving, as well as feelings, concerns and expectations about the process, such as the potential for recipients to feel indebted and their subsequent desire to somehow reciprocate (Sque and Payne 1994, Fox and Swazey 2002).

However, despite the apparent similarities with gifting, the theory of gift exchange has primarily only been discussed from a cadaveric perspective and the relevance of this theory, particularly in the context of live kidney transplantation, has never been empirically tested. This chapter will therefore explore whether the gift exchange theory provides an appropriate framework for understanding the live transplantation process and, if so, the potential usefulness of this to clinical practice and research.

10.2 Giving

For a gift to be a gift, it has to be the givers to give (Gerrand 1994). In cadaveric transplantation, even though the organs(s) belongs to the donor, it is not the donor who gives, or even consents to giving (as they are dead), but the donor’s family. This is one of the fundamental reasons why the analogy between gifting and cadaveric transplantation has been questioned. However, in live transplantation, the kidney belongs to the donor and it is, therefore, theirs to give, in theory, to whomever they please.

To properly assess whether a live kidney transplant constitutes a ‘gift’ in the Maussian sense, it is first necessary to explore the circumstances in which giving (i.e. donating) occurs. The decision making process in live donors (how the
decision to donate is made) has been subject to considerable interest and research, primarily because of the assumption that some donors may feel emotionally compelled to donate a kidney to help a loved one in need (Lamb 1996, Fox and Swazey 2002). If donors are pressurised to donate, either by others (e.g., the recipient or health professionals) or from their own internal belief system (e.g., feelings of guilt or obligation), it could affect their ability to provide informed consent to transplantation (Siminoff and Chillag 1999, Eggeling 2000, Olbrisch et al 2001). Furthermore, if the donor was coerced in any way, the donation would not be sufficiently voluntary to be called a gift (Gerrand 1994, Godbout and Caille 2000). After all, a gift that is imposed is not really a gift.

As discussed in chapter three, research has characterised live donors’ decision making into 3 patterns; moral or straightforward (instantaneous with little or no deliberation), deliberative (a period of deliberation before a conscious decision is made) and postponement (no real decision made, decision made for them not by them) (Simmons et al 1987).

Multiple studies have shown that most donors (on average 74-86%), and in some cases all, make an instantaneous, voluntary decision to donate, with little or no deliberation and experience no pressure from others to do so (Sadler 1973, Higgerson and Bulechek 1982, Morris et al 1987, Simmons et al 1987, Schover et al 1997, Karrfelt et al 1998, Eggeling 1999 a, b, 2000, Fehrman-Ekholm et al 2000, Cabrer et al 2003, Schweitzer et al 2003, Stothers et al 2005). Furthermore,
as in this study, donors generally do not regret making this decision, regardless
of clinical outcome (e.g., D3) or complications (e.g., D11).

The speed with which most donors initially make their decision to donate,
perhaps when they are not even in full possession of the facts, is an indication
that the decision making process is moral rather than deliberative (Eggeling
the decision to donate easy and are strongly motivated and comfortable without
extensive deliberation (Simmons et al 1987). This and other studies also show
that all (or most) donors feel well informed about transplantation, are happy to
have donated and, given the choice, would donate again in similar circumstances,
if it were possible (Sadler 1973, Simmons et al 1987, Morris et al 1987, Gouge et

Furthermore, most donors do not typically view their actions as brave or heroic
(Schweitzer et al 2003, Stothers et al 2005). All donors in this study felt that
donating was just a normal, natural thing that one person would do to help
another person they care for:

"Some people say, oh you're incredibly brave, but I don't think anyone
can understand until you're in that situation, exactly what you would
decide. I think most people, given all the things that I'm faced with, would
do the same really."
(D6, wife, 1st interview).

Many academics and clinicians often question donors’ attitudes towards donation
as they feel that, despite multiple evidence to the contrary, their decision to
donate must, in someway, be difficult, complex and extraordinary. However, as Crouch and Elliott (1999) state:

‘If we are ever to clarify the nature of voluntarieness we must recognise that moral and emotional commitments are not exceptional or constraints of freedom but rather are a part of ordinary human life. More specifically they are part of ordinary family life that we must take seriously if we want to understand how family members can make free choices about organ donation. In these circumstances it would appear that the interests of family members are often inextricably intertwined with that of the individual’ (p. 278).

There were no instances of family conflict regarding donors’ decision making in this study. However, most donors were either spousal, and therefore married to the recipient, or single. Consequently, it was not possible to explore the views of ‘significant other’ family members who were not actually involved in transplantation. But despite the relative ease with which most donors make the decision to donate, approximately 20-25% of prospective donors deliberate somewhat over their decision and an even smaller proportion (approximately 1-5%) postpone decision making completely (Simmons et al 1987, Schover et al 1997, Stothers et al 2005). In this study, there was only one instance of deliberative decision making. D4, who initially made an instantaneous, voluntary decision to donate after his other sister withdrew from the process, subsequently spent several months contemplating his decision to donate, before deciding that it was the right thing to do:

"The phase of pre-transplant tests is quite important because it gives you 3 months of... consideration time before you even know that you are compatible. And that's probably quite useful. The time in between the tests were good for me because they allowed me to think about the transplant. You make a decision early on but I think in my case it was good to have a long period to consider it and I felt at the time that it was the right thing to do and I feel the same now."

(D4, brother, 1st, 2nd and final interview).
D4 could not provide a definitive rationale for this decision making process and, as he was the only donor in the study who deliberated, and his concerns about donation were no different and apparently of no greater magnitude than other donors, it is difficult to conclusively establish the exact reasons for this. However, it has been suggested that deliberation is more likely to occur the more distant the relationship is between donor and recipient, as the desire and motivation to donate may be less strongly felt (Olbrisch et al 2001).

Once donors have volunteered to donate, they may (as D4 found) subsequently find it difficult to withdraw from the process, even if they want to, because of the expectations of others (e.g., the recipient) and/or feelings of guilt or personal responsibility. Pre-transplant ambivalence may also increase the likelihood that donors will view the transplant negatively afterwards (Simmons et al 1987). However, research has shown that, with time and support, most donors eventually make a decision that they are happy with and, consequently, few experience psychosocial problems associated with decision making or donation (Schover et al 1997, Schweitzer et al 2003).

As this study shows, most live donors do have a variety of concerns about transplantation that they have to address before donation. Common concerns include, fear of surgery, pain, implications for future health, the recipient’s well being and rejection or failure of the transplant (Hiller et al 1998, Burroughs et al 2003, Calder and Chang 2004). If these concerns are not adequately addressed, they can cause fear and anxiety, which may affect the donor’s ability to proceed with the transplant (Hiller et al 1998). It is therefore imperative that health
professionals develop effective strategies to identify and address these concerns and ensure that prospective donors are properly prepared and informed for transplantation and given sufficient time and support to make their decisions.

However, although how donors make the decision to donate has been subject to considerable research, in contrast, factors that motivate donation have been subject to relatively little research. This is perhaps anomalous, since understanding what motivates people to donate seems essential to understanding how they make the decision to donate.

In this study, there were no instances of 'black sheep donors' or 'conditional giving' (e.g., 'giving with strings', or with specific expectations). The definition of a gift is the voluntary transfer of 'property' (real or personal) without valuable consideration or explicit expectations of recompense (Dictionary.Com 2006). Gift giving is also thought to involve some degree of generosity and is commonly undertaken to benefit the recipient. Therefore, if giving occurs in any of the above circumstances, it is doubtful whether the kidney could be regarded as a gift by either party (Gerrand 1994).

Furthermore, no donors donated because they felt obliged to, morally or otherwise:

"I never felt, at any stage, that it was something that I had to do and my husband has never pushed me. It's just I want what's best for him and if I can help him by doing this, then great. I'm the sort of person that I make choices on what seems the right thing at the time. And to me this seems the right thing, you know. But it's not so much a decision as I feel it's the right thing to do. I didn't have to rack my mind thinking about it, like should I or shouldn't I?"
(D6, wife, 1st interview).
Feeling obliged to donate would, perhaps, indicate an element of coercion. Consequently, giving in such circumstances would probably not be sufficiently voluntary to be called a gift (Gerrand 1994, Godbout and Caille 2000). However, these data suggest that live kidney transplantation, much like contemporary gift giving between family and friends, is strongly motivated by a desire to give (donate) because the donor wants to, rather than because they feel obliged to. The prime motivating factor for donating in most live donors (and all in this study), is altruism; a desire to help restore the health of a loved one in need (Higgerson and Bulechek 1982, Hilton and Starzomski 1994, Hiller et al 1998, Eggeling 1999a, b, 2000).

This study also provides a unique insight into factors that influence spousal donation; an area that has, so far, been subject to very little empirical research. Personal commitments to partners may influence spouses to donate because, amongst other things, it provides an opportunity to become more of a partner and less of a nurse (Nolan 1999, Olbrisch et al 2001). However, spousal donors in this study were particularly motivated to donate to help restore the health of their partners, not just for the recipient's benefit, but also to help restore their life together as a couple:

"We like to go on our holidays and hopefully when this is done, we’re not going have all that messing around with dialysis. It’s kind of selfish in a way but I want her to be right...and if I can help, then great."

(D1, husband, 1st interview)

Altruism is desirable because its absence is potentially destructive to society (Swales 1997). However, whether true altruism (i.e., genuine selflessness) exists is questionable, since people often have egoistic reasons for being altruistic
Live transplantation, like personal gifts, can benefit the other and the self and can, therefore, help to sustain mutually desirable relationships (Murray 1987). In these spousal donors, it would appear that donation was motivated by a tacit amalgam of altruism and self interest. However, this did not have a detrimental effect on donor-recipient relationships as both parties recognised that the transplant was mutually beneficial.

'Altruistic gestures toward others are invariably tempered by the after effect of realising that one's own self interest must be bound up somewhere, if only in maintaining one's social environment' (Strathern 1992, p.130).

There was also one instance of reverse reciprocity in this study (D2). Although D2’s main reasons for donating to his wife were the same as all other donors, including spousal, he also maintained that he wanted to give because he felt that he owed her so much for what she had done for him throughout their marriage. A similar finding was also reported by Lessor (1993) in a study of ova donation between sisters, where one sister reportedly donated ovas to her sister as a way of ‘repaying’ her for helping her out so much over the years.

10.3 Receiving

Research into decision making in live transplantation has primarily focused on the donors’ perspectives, mainly because of concerns, largely unfounded, that this decision was, in someway, difficult and, perhaps, not totally free. In contrast, the recipients’ decision making process (i.e. why and how they decide to accept the offer of a transplant) has been subject to virtually no research. Consequently, this process is poorly understood and, as the data in this study demonstrate, is
often far more complex and arduous than the relatively straightforward decisions made by most donors.

Prospective recipients generally view transplantation as the best treatment option, and believe that a successful transplant will provide them with a better quality of life and the potential to return to a relatively 'normal existence', free from dialysis and the problems associated with ESRD (Murray and Conrad 1999, Schweitzer et al 2003). Recipients in this study also recognised the potential benefits of live transplantation (e.g., improved graft survival rates) and, in spousal recipients in particular, there was a belief, as with their donors, that a successful transplant would help to restore their family life. It was, therefore, for these reasons that recipients wanted a live transplant.

When successfully transplanted, an organ may actually save the recipient’s life, or at the very least transform it (as in this study), so the 'gift' in transplantation is not merely the organ, but also 'life' itself (Deguchi 2002). Consequently, it is, perhaps, unsurprising that recipients feel incredibly grateful to donors for their offer of donation:

"It kind of blew me away really because we were with the doctor back in February 2003 and she said this will be the year it's going to happen and [D10] just blurted out and said what if I could be a live donor? It was all her instigation. I was just blown away, what could I be but entirely grateful. As far as I'm concerned she's given me another life really."

(R10, husband, 1st interview).

As in gift exchange, once a live transplant is offered to a prospective recipient, they are under some obligation to accept it (Fox and Swazey 2002). In theory, they can refuse but to do so would reduce the opportunity of improved health, or
even life, and would also perhaps imply a rejection of the donor (Fox and Swazey 2002). However, despite the desire for a kidney transplant, most, if not all, recipients find accepting a loved one’s offer of donation emotionally burdensome, primarily because of concern for their health and wellbeing and the impact that graft rejection might have on them, should it occur (Salmons 1980, Hilton and Starzomski 1994, Murray and Conrad 1999, Franklin and Crombie 2003, Schweitzer et al 2003).

"I'm just concerned with dad going through it and that's playing on my mind. If dad gives the kidney and something goes wrong with him, then I've got to live with his kidney in me. How am I going to live with my mum, sister and the rest of my family? Because my dad has given his life for a kidney for me to live and I'm upset about that."

(R11, son, 1st interview).

Data from this and other studies (e.g., Hilton and Starzomski 1994, Murray and Conrad 1999, Schweitzer et al 2003) suggest that concern for donors is a significant impediment to prospective recipients accepting the offer of a live transplant. If left unaddressed, this concern could also, potentially, prove to be a significant obstacle to improving the rates of live transplantation. Consequently, recipients may need to be reassured by donors that they really do want to proceed with the transplant, before they can properly consider their offer (Hilton and Starzomski 1994, Schweitzer et al 2003). Health professionals should also recognise how difficult this decision can be for prospective recipients and should, therefore, provide them with the appropriate care, information and support to facilitate their decision making.

Whilst most recipients eventually agree to a live transplant, primarily because of the benefits and the donor’s willingness, they often completely reject offers of
transplants from certain family members, such as children, or those with responsibilities for others (e.g., those with their own children), because of insuperable concern for them (Olbrisch et al 2001). Data also suggest that recipients generally do not want the responsibility of requesting a transplant, probably because they want to avoid feeling unduly indebted to the donor (Olbrisch et al 2001).

Recipients in this study also made it clear that they would only accept a transplant from certain family members because they were giving 'unconditionally'. It would therefore appear that giving 'with strings' is something that recipients would prefer to avoid, perhaps at all costs, as the transplant would represent a 'gift' that could never be repaid. Besides, a gift that is given 'conditionally' is not really a gift at all and would probably not be viewed as such by the recipient or the donor.

Consequently, in this study, recipients wanted donors to give because they genuinely wanted to, not because they felt obliged to. They were all, therefore, at pains to point out that they had not pressurised the donor in any way and had made it clear to them that they could back out at any time if they so wished:

"He's made up his own mind to do it, because I could never ask anybody for a kidney, how can you? But I have to say he's the only person I would be happy to have one from, because he's doing it altruistically and I know he's not afraid to do it. To be given one by someone who really doesn't really want to, who is doing it just because they think they should, I don't think is a very good thing.

I just don't think you can take that responsibility of taking somebody's kidney.... [D1] is very sensible and he knows that the other one will counteract it. If your mindset isn't right it wouldn't be any good. My brother has never mentioned it and if you've never mentioned it you're not going to want to give one. I think my sister would have done it out of
duty but I'm not sure I'd have wanted one from duty. I'd have wanted her to do it because she felt that it's the right thing for my future life." (R1, wife, 1st interview).

Health professionals therefore need to be aware of the reasons why and how recipients make decisions about live transplants and from whom they will, and won’t, accept an organ (Murray and Conrad 1999):

However, whilst some donors may give 'conditionally' (e.g., as a way of controlling the recipient), the converse may also be true. That is, some recipients may expect a transplant from certain donors because they feel they 'owe it to them'. If a donor was exploited by a recipient in such a way, it is unlikely that either party would view the transplant as a 'gift' (Godbout and Caille 2000).

Research has shown, however, that most recipients view the transplant experience positively and very few regret having a live transplant (Gouge et al 1990, Burroughs et al 2003, Schweitzer et al 2003). But, whilst the transplant rarely causes psychosocial problems, particularly between recipients and donors, the gift of an organ often creates feelings of identification, indebtedness and a special kind of responsibility in recipients (Fox and Swazey 2002). Indeed, receiving an organ from a related donor appears to have all of the key features associated with gifting in contemporary society, in that it involves a certain amount of implicit 'etiquette'.

As in traditional gifting, an implicit obligation of recipients could be described as 'grateful conduct', which at a minimum includes acceptance of the transplant, as well as some expression of gratitude (Murray 1987, Gerrand 1994). In this study,
the lives of all recipients were transformed following successful transplantation
and, subsequently, they were able to do things that they had not been able to do
in years, such as exercise and gardening. Consequently, because of the impact of
the transplant and the donor's personal sacrifice, all recipients, regardless of
clinical outcome, felt incredibly grateful to their donor for donating. Therefore,
all had, at various stages, thanked their donor for the transplant:

"I really can’t thank him enough for what he’s done. I’ve thanked him
obviously, but I can’t really thank him enough. But he knows that
obviously. What can I say... I suppose I’m so grateful for what he’s done
for me... and he’s been through a lot for me really."

(R2, wife, 2nd and final interviews).

Another implicit obligation of recipients, again as in traditional gifting, is
‘grateful use’ (Murray 1987). This essentially means that recipients are expected
to ‘look after’ the kidney that they have been given. All recipients felt that it was
important to take care of their transplant, although none spoke about it being an
expectation of the donor and no donors discussed this aspect at all, perhaps
because the expectation is implicit and recipients were behaving responsibly.
However, imagine if the recipient did not ‘look after’ their transplant (e.g.,
stopped taking their anti-rejection medication), how would the donor then feel?

"You hear these stories of what happens to people who do give, one
about that woman who got beaten up by her son. That was awful. She
gave one to her teenage son, so of course when he got this new kidney he
went boozing and playing up. She used to have rows with him about it,
'I've given you my kidney you respect it', so he beat her up.... So we
obviously want to avoid that sort of thing”

(R1, wife, 1st interview).

As in contemporary gifting, receiving, like giving, carries with it certain tacit
‘rules’ that the receiver and the giver rarely discuss, or even acknowledge. But if
these ‘unwritten rules’ are disregarded it can affect all those concerned with the
gift. A certain amount of 'etiquette' is inherently expected of recipients and, given the nature of what has been given, some may find this expectation potentially overwhelming. However, failure to 'respect' the gift may have a detrimental effect on the recipient's health and may also affect the donor's feelings:

'It would be wrong to treat something dear to the donor in an undignified manner, as merely a commodity. Likewise, it would be wrong to use it in a way the donor would disapprove of. Simply recall an occasion when someone treated with indifference a gift that you had regarded as special and important, in some way the rejection of the gift was a personal rejection. This is even truer in gifts of the body' (Murray 1987, p 32).

10.4 Reciprocation

Whilst giving and receiving are irrefutable features of live transplantation, whether or not reciprocation occurs in a meaningful way that satisfies both giver and receiver is questionable. The problem of receiving a gift of such magnitude as an organ is that it is inherently beyond reciprocation (Smith 1998, Siminoff and Chillag 1999, Fox and Swazey 2002). Particularly in a material sense, since any form of payment for human organs is illegal in the developed world (Sque and Payne 1994). Even if recipients were to attempt to reciprocate, what counter gift could adequately commensurate with what they have been given?

Consequently, some recipients may be left feeling unduly indebted to the donor and may, therefore, experience psychosocial problems, such as feelings of guilt, disequilibrium and relationship problems (Salmons 1980, Simmons et al 1987, Sque and Payne 1994, Siminoff and Chillag 1999, Fox and Swazey 2002, Crombie and Franklin 2006). This is what Fox and Swazey (2002) refer to as 'the tyranny of the gift’. A debt, that by its nature cannot be repaid, is fundamentally
threatening to the social order (Siminoff and Chillag 1999). Feelings of indebtedness may also be further exacerbated if the donor gave conditionally or if they exhibit a proprietary interest in the recipient’s life, health and wellbeing post transplant (Smith 1998).

Combined data from two British qualitative studies found that some adolescent live transplant recipients, who had received parental grafts, reported feelings of obligation to their donor, which resulted in some psychological distress and social-familial alienation, although no such incidences were reported in sibling recipients (Franklin and Crombie 2003). Yet this and other studies have found that relationships between donors and recipients rarely deteriorate or become problematic post transplant; in fact, they usually remain the same, or even improve (Higgerson and Bulechek 1982, Simmons et al 1987, Hilton and Starzomski 1994, Schover et al 1997, Jacobs et al 1998, Karrfelt et al 1998, Burroughs et al 2003, Schweitzer et al 2003):

"I don't think our relationship has changed really through all of this. It was good before and I don't want her to feel that anything's changed really. So I'd say it hasn't changed at all.... I don't feel any different to her, I loved her before...... and I don't think I could love her anymore so it doesn't alter it really."

(R9, 1st and 2nd interview).

Therefore, if live transplantation constitutes a gift in the Maussian sense, the fact that donor-recipient relationships are generally uncomplicated after transplantation, would, perhaps, indicate that some form of meaningful reciprocation has occurred.
It has been argued that, despite transplantation being inherently unrequitable, it
does not eliminate the impulse to repay; in fact it often magnifies the propensity,
although usually in slightly different ways (Siminoff and Chillag 1999). Just
what constitutes ‘appropriate reciprocation’ depends on cultural norms and the
specifics of the relationship (Murray 1987). It has been postulated, however, that
the way in which recipients first attempt to deal with their sense of obligation, is
to express their gratitude to the donor and this, it is maintained, is a non-material
form of reciprocation (Bartucci and Seller 1988, Vernale and Packard 1990, Sque
2002).

In this study, recipients were profoundly grateful to the donors for donating,
particularly as the transplant, where successful, had significantly improved their
lives. Consequently, all had thanked the donors, at various stages, for donating.
As in traditional gift exchange, it would appear that this is an important implicit
expectation in live transplantation. Whilst donors may not expect the recipients
to be obsequious towards them, research has shown that when recipients do not
express a reasonable amount of gratitude (although what constitutes ‘reasonable’
is unclear) donors often feel angry and used (Simmons et al 1987, Schover et al
1997).

But in and of itself, is the mere expression of gratitude a sufficient form of
reciprocation? Data suggest that, whilst potentially important, showing some
degree of appreciation is not the only, nor is it the most significant, form of non-
material reciprocation. All donors in this study were delighted with how the
recipients’ lives had improved since transplantation and, consequently, they derived an immense sense of personal satisfaction from having donated:

"I always felt that it was the right thing to do and having gone through everything now I know that it was. I feel very proud to have donated to my sister and the whole experience has been very positive for me, well for all of us I think.

When I see her I feel really proud about what I’ve done.... It’s like an amazing experience, you feel like you’ve done something really worthwhile in your life.... I feel like it’s maximum gains for my sister, her husband and me because the way it’s made me feel with relatively little cost... it wasn’t too high a price to pay.

It still makes me feel pretty good, to know I did it. I feel very proud to see my sister so much better. Her health has massively improved. I can see how much it has improved their life now and also her two boys. You know there’s been a massive improvement in their lifestyle and that’s invaluable.

I think the way I still feel about the whole thing, and what I’ve gained from it personally and what my sister has gained from it, far outweighs any possible concerns that I have. It’s quite a big thing to feel so instrumental in improving somebody’s quality of life. That is something that I can fall back on, you know, like sometimes in work when you are bothered about things or financial things you think that it’s quite a good grounding and it helps to keep things in perspective."

(D4, 2nd and final interviews).

By the very nature of what has been given, donors clearly cannot receive the equivalence of what they have given. Similarly, the gift will never be reciprocated in an economic sense; there is no equivalence, nothing tangible is returned (Godbout and Caille 2000). However, this ‘joy of giving’ is, arguably, the most significant form of non-material reciprocation for donors and helps to confirm to them that what they did was worthwhile. Godbout and Caille (2000) state:

‘However unilateral this may appear, research indicates that the donors’ return is enormous, even if what is returned is implicit in the act itself and is not embodied in any specific object or service. Something which would be impossible since, in the material sense, neither one exists. Donors are often transformed by their donation. The unusual return doubtless
explains why, despite its apparently unbalanced, un-reciprocal, 'impulsive' nature, the gift rarely causes problems between donors and recipients. On the contrary, it often draws them closer together' (p. 90).


It would therefore appear that live transplantation is intrinsically rewarding for most donors. Furthermore, seeing the recipient looking so well and getting on with their lives on a regular, or even daily basis, perhaps constantly reinforces the donor’s internal feelings of happiness and personal satisfaction. This continual corroboration for donors perhaps represents a ‘gift that keeps on giving’. Many people around the donor, such as family, friends and the recipient, often also positively reinforce how laudable their actions were (Simmons et al 1987). Therefore, regardless of whether donors actually want or even value such praise, their actions are also often regularly externally verified and praised.
As discussed in the literature review, a similar phenomenon is also found in voluntary workers (e.g., AA members) and regular blood donors, who often insist that the pleasure of giving is one of the prime motivating factors for their actions (Godbout and Caille 2000). Besides the other non-material returns from giving, such as the gratitude and appreciation it inspires, the return for most donors is contained in the act of giving itself and many are personally transformed by the act of donation. In live transplantation:

'The return, non-existent in other forms of circulation, is part and parcel of the act of giving. To give is to reciprocate. From the perspective of the usual logic of exchange, the most astonishing return is that which the donor receives from giving' (Godbout and Caille 2000, p.97).

Because of how grateful recipients felt to donors for donating and the impact that the transplant had had on their lives, recipients, and donors, felt that there was a potential for the transplant to affect their relationships with each other. However, as already discussed, donor-recipient relationships usually remain the same or improve post-transplant and rarely deteriorate (Burroughs et al 2003). One of the ways this is achieved, given the unreturnable nature of the gift, is for donors to minimise the recipients’ desire to show them gratitude (Murray 1987, Simmons et al 1987).

Consequently, donors significantly downplay their actions and maintain that the recipients do not owe them anything. This is analogous to the ‘etiquette’ of contemporary gifting, whereby gift givers often try to lessen the value of their gift by saying things such as ‘it’s nothing special’ (Murray 1987). The reason for this behaviour is to ensure that recipients are not embarrassed by or unduly
grateful for the gift, but, particularly in live transplantation, it may also indicate
the importance of the relationship to the donor (Murray 1987).

Furthermore, despite the way in which donors and recipients felt about the
transplant and how it had affected their lives, they tended not to have any
profound discussions about it post-transplant. A similar finding was also reported
by Eggeling (2000), although she did not probe her participants further to clarify
the reasons for this. However, in this study, this behaviour occurred because, in
donors especially, there was a belief that everyone, especially recipients, needed
to ‘move on with their lives’.

“We don’t talk about it much now, if at all really. I think that’s best to be
honest. It’s over and done with now, time to move on.”
(D11, father, final interview).

10.5 Discussion

Whilst the live transplantation process in this study has the essential features of
gift exchange, by the very nature of what is given and received, the process is far
more complex than the exchange of material gifts originally described by Mauss
(1990). Consequently, there are some fundamental differences in the legitimate
exchange of live human organs and the exchange of material gifts.

One of the key differences relates to the lack of freedom of giving and receiving,
due to factors in the procurement process (Conrad and Murray 1999). Unlike
traditional gifting, organ transplantation takes place within an interpersonal
network that includes donors, recipients, their families and health professionals
(Conrad and Murray 1999). Health professionals (‘gatekeepers’) working in the
field of transplantation, essentially mediate and ultimately decide, using agreed
criteria, who can and cannot give and to whom they may give. This, of course, does not feature in traditional gifting, where the giver is, in theory, free to give to whomever they please:

'The freedom to give or to receive an organ is neither absolute or random. These freedoms are mediated and governed by the norms of gift exchange on the one hand and by a biological and psychosocial screening process, referred to as 'gate keeping', on the other. No individual is therefore totally free to give or to receive organs' (Fox and Swazey 2002, p. 5).

Furthermore, live transplantation does not establish a new relationship, as it often did in exchanges originally described by Mauss (1990), but rather it takes place because of the existing relationship between donor and recipient (Gerrand 1994). However, as this study shows, the gift of an organ, much like contemporary gifts between family and friends, can significantly sustain the bond between donor and recipient, which is, of course, the fundamental raison d'etre of gifting.

Live transplantation is also generally voluntary, not obligatory, as in traditional gift exchange, although, as discussed, certain implicit obligations do appear to exist. Also, in an act of giving as significant as the donation of a kidney, donors do not behave in accordance with conventional utilitarian theories. They do not calculate what they will receive by giving, for example, in systems of competitive exchanges such as kula or potlatch, where the specific purpose of the exchange is to receive more in counter gifts than one has given. But rather live donors appear to:

'Act completely outside this explicative model for human behaviour. Live transplantation is a modern gift if ever there was one, but it calls into question the deliberative utilitarian model, where the means are chosen rationally with an end in view. Organ donation shows that the gift is a moral act and as such is intrinsically motivated and not subject to means-end analysis' (Godbout and Caille 2000, p. 90-91).
The potential relevance of the gift exchange theory to the live transplantation process may also be significantly related to a variety of factors, particularly the motivation for giving and the relationships between donors and recipients. In this study, all donors and recipients had very good, pre-existing relationships with each other and were either married or genetically related. However, where the relationship between the two is problematic or if transplantation occurs where the donor has given ‘conditionally’ or where recipients extorted a kidney from the donor because they felt that they ‘owed them’, it is extremely unlikely that the transplant would constitute a gift.

The impact of the ‘gift’ is also probably dependent on the success of the transplant. When the transplant is unsuccessful the donor and recipient may experience great difficulty in making sense of the exchange (Franklin and Crombie 2003). For example, the effects of the transplant on family 3 were not as profound as in other families because of the graft rejection. Their motives for giving and receiving were the same as other families and R3 was grateful to her husband for donating. D3 also had no regrets about donating and derived some pleasure from having given. However, because of the graft failure, the transformation in R3’s life post-transplant obviously did not occur as it did in other recipients. Consequently, the ‘gift’ did not affect their lives as significantly. Therefore, the ‘joy of giving’ was obviously not as apparent in D3.

There can be little doubt, though, that based on the available evidence, live organ transplantation (as described here) is one of the most dramatic and supreme forms of gift giving existing in contemporary society (Fox and Swazey 2002).
The data from this study also suggest that, in terms of an exchange model, live transplantation has all of the essential psychosocial dynamics of contemporary gifting (Vernale and Packard 1990, Hilton and Starzomski 1994, Sque and Payne 1994, Conrad and Murray 1999, Fox and Swazey 2002).

Therefore, the concept of gift exchange does, I believe, provide a useful framework for understanding the live transplantation process. In particular, it provides a theoretical framework for understanding the feelings and concerns of those involved in the process, particularly in relation to giving, receiving and reciprocating (e.g., feelings indebtedness and a desire to repay). It offers nurses a useful framework to understand and predict the expectations and stresses that accompany the decisions of donors and their desire to give and the recipient in their desire to receive and repay (Sque and Payne 1994). This improved understanding of the live transplantation process can, therefore, help to inform and further develop clinical practice. In particular, it may help health professionals to provide guidance, information, help and support to donors and recipients, which may help them to realise that their feelings and concerns are normal; thus helping them to feel less alienated in the unusual and difficult circumstances in which they find themselves (Sque and Payne 1994, Olbrisch et al 2001).

10.6 Conclusion

The experience of these participants resembled the expected consequences of gift exchange and supports the hypothesis that live transplantation represents a contemporary gift, thus providing a logical explanation of their experiences. The
resultant improved understanding of this process can, subsequently, be used to inform and develop clinical practice and future research in this area, as well as further developing the theory of gift exchange, particularly in the context of live transplantation.

This chapter has explored the concept of gifting in relation to live transplantation. In the next and final chapter, findings from the study are drawn together and discussed in relation to the literature reviewed in this thesis, and implications from the study to practice and future research.
CHAPTER ELEVEN: Conclusions and recommendations for future clinical practice and research

11.1 Introduction

To summarise this thesis, in chapter one, the concept of gift exchange was explored and in chapter two, this theory was examined in relation to healthcare, focusing specifically on live kidney transplantation. In chapter three, the live transplantation experience, from the perspectives of donors, recipients and 'significant others', was discussed. Chapter four subsequently discussed approaches to the study design and methodological issues. Chapters five, six and seven presented, respectively, data from the three phases of interviewing; pre-transplant and 3 and 10 months post-transplant. In chapters eight, nine and ten, data were interpreted and explored in relation to service provision issues, key study findings and the gift exchange process, as applied to live transplantation.

This final chapter will discuss whether the research has answered the research questions and to what extent this study has enhanced or modified knowledge and understanding about the study phenomena. This study was originally undertaken to explore donor and recipient experiences of live transplantation, immediately before and in the first year after transplantation, primarily because of the lack of existing research in this particular area. The aims of the study were to explore:

- The experiences of donors and recipients throughout the live transplantation process
- The relevance of the anthropological theory of 'gift exchange' as a framework for exploring and understanding the live kidney transplantation process
- How a theoretically informed insight into these experiences may be used to inform and develop future research and clinical practice
To conclude, this chapter will, therefore, firstly summarise participants’ experiences of live transplantation. The main study findings will then be brought together and compared with existing, relevant research and literature. Finally, recommendations arising from this study for future clinical practice and research in this area will be presented.

11.2 Participants’ experiences of live transplantation

The live transplant experience was generally positive for all participants, although a variety of issues caused anxiety and distress to some, and occasionally, all participants. Live kidney transplantation was viewed as the best treatment option by all participants, particularly recipients.

All donors initially made instantaneous, voluntary decisions to donate, free from any external pressure. Furthermore, they generally found this decision easy to make, were happy with it and, regardless of outcome (D3) or personal complications (D11), had no regrets about donating. Conversely, recipients found accepting the donor’s offer of a transplant emotionally troublesome, primarily because of concern for their health and wellbeing. They were only really able to accept the transplant after being reassured by donors that it was something that they really wanted to do.

Whilst the transplant procedure was relatively straightforward, many participants experienced complications associated with the procedure, such as pain, wound problems and acute graft rejection, which was untreatable in R3.
Despite being the treatment of choice, transplantation caused a variety of concerns for all participants, particularly recipients, the most significant and common being the fear of graft rejection or failure. This concern was most significant before and in the first few months after transplantation and was particularly exacerbated by an episode of acute graft rejection. However, participants recognised that the prospect of graft rejection was essentially beyond their personal control, and subsequently dealt with this fear by using emotion focused styles of coping, such as denial and avoidance. By the final interviews, these concerns had diminished somewhat and participants were subsequently able to start making plans for the future.

Successful transplantation profoundly affected the lives of all recipients. Their personal lives and, therefore, also their family lives, were transformed post-transplant and all were subsequently able to do things that they had not been able to do for years, such as gardening and exercise. Consequently, recipients were extremely grateful to their donors for donating and had thanked them at various stages. In turn, donors derived immense personal satisfaction from having donated, which also helped to confirm to them that what they had done had been worthwhile. However, to minimise the sense of ‘indebtedness’ that all recipients experienced, particularly post-transplant, donors ‘downplayed’ their actions and tended not to discuss the transplant, in an effort to ‘move on’.

However, transplantation, when unsuccessful, was found to be devastating. The rejection experience for family 3 was so profound that it caused severe depression and even induced suicidal feelings in R3, although no known attempt
was made to commit suicide. But with time, support and improved physical health, she too was able to get on with her life. It is perhaps interesting to note that, despite this experience, family 3 had no regrets about proceeding with transplantation and still viewed it as the best treatment option.

By the final interviews, all participants were getting back to a 'normal existence' and were making medium term plans for the future. Throughout this process, the transplant service and certain health professionals were generally praised by participants. However, a number of recommendations for service development were made, including the need for improved follow up care for donors, the availability of a dedicated counsellor and improved provision of information (e.g., written information leaflets about the pre-operative and discharge phase). R3 also felt that the way in which prospective recipients were prepared for transplantation, particularly through the provision of information, needed to improve, as did the emotional support provided following graft rejection.

11.3 Relationship of findings to previous research and their contribution to the body of knowledge

Whilst certain aspects of the live transplantation process (e.g., how donors make the decision to donate) have been relatively well researched, most of this research has largely been survey based, retrospective studies. Relatively few studies have explored the personal dimensions of live transplantation, from the perspective of donors and recipients. This study was, therefore, quite unique, in that it explored, longitudinally, the experiences of donors and recipients,
throughout the transplant process, before and in the first year after transplantation.

Whilst many authors (Murray 1987, Vernale and Packard 1990, Hilton and Starzomski 1994, Sque and Payne 1994, Siminoff and Chilag 1999, Fox and Swazey 2002) have offered constructive theoretical insights, often based on anecdotal evidence and/or clinical experience, into the apparent analogy between gifting and organ transplantation, no empirical testing of this theory could be found in the literature. This study has, therefore, extended the knowledge and understanding of this process by providing an empirically based explanation of donor and recipient experiences of live transplantation, within a framework of Mauss's (1990) gift exchange theory.

Data from this study show that gifting provides an expedient framework for understanding factors that motivate giving, receiving and reciprocating in live transplantation. In these participants, although occasionally subtly different due to the nature of 'the gift', live kidney transplants had the same psychosocial dynamics and implicit etiquette as contemporary gifting between family and friends.

The relative speed and ease with which donors initially made their decision to donate support findings from other studies (Simmons et al 1987, Schover et al 1997, Eggeling 1999a, Schweitzer et al 2003, Stothers et al 2005). However, this study provides an additional insight into factors that motivate donation in genetically related and spousal donors that has seldom been explored before. The
desire to donate was strong and moral and motivated by altruism (wanting to help restore the health of recipients) and also, in spousal donors, egoism (a desire to restore one’s family life).

The large volume of research into donors’ decision making process has largely occurred because of concern for their physical and psychosocial wellbeing (Fox and Swazey 2002). However, as this and multiple other studies have shown, most donors find the decision to donate easy, relatively straightforward and uncomplicated (Simmons et al 1987, Karrfelt et al 1998, Fehrman-Ekholm et al 2000, Cabrer et al 2003). Furthermore, after donation most donors are happy to have donated, have no regrets about doing so and would, in theory, do it again if it were possible (Simmons et al 1987, Schweitzer et al 2003, Stothers et al 2005). Consequently, as the risks to donors are relatively low, it would seem reasonable to argue that live donation is morally justified, providing the donor’s decision is free, voluntary and informed (Ross 2000). Given the similarities in study findings in this area, it is perhaps questionable whether further research needs to be conducted into this specific area in future. As motivations for donation are often different between related and genetically unrelated donors, the donor assessment protocol may also need to be different; consequently, further research about the characteristics and motivations of donors would seem to be more appropriate (Olbrisch et al 2002).

This and other studies (Simmons et al 1987, Schover et al 1997, Stothers et al 2005) also demonstrate that a small proportion of donors deliberate before making a decision about donation. As only D4 deliberated in this study, and as he
was unable to clarify precisely why this was so, there is undoubtedly a need to
better understand this process from the donor’s perspective. However, what this
study does show is that deliberation can significantly increase the pressure on
donors to donate, both from their internal belief system and indirectly from
families’ hopes and expectations.

It is therefore important that all prospective donors are adequately informed and
supported throughout this process and, wherever possible, provided with
sufficient time to contemplate their decision (Schweitzer et al 2003, Calder and
Chang 2004). However, the data also show that once D4 had offered to donate,
the pressure and expectations of others was such that he felt it was virtually
impossible to withdraw from the process, even if he wanted to. Consequently,
whilst contentious, offering donors a valid ‘face saving medical excuse’ to
withdraw from the process, if they feel that they cannot proceed, may be morally
justified (Calder and Chang 2004).

The decision making process for recipients in this study was troublesome and
complex due to their concern for the donors, yet this area has been subject to
virtually no research. What this and other studies demonstrate is the importance
of reassurance from live donors in helping recipients accept the offer of a
transplant (Hilton and Starzomski 1994, Schweitzer et al 2003). Therefore, where
possible, providing donors are genuinely happy to proceed with the transplant, it
may be helpful if donors are encouraged to speak with the recipients to facilitate
their decision making. It may also be helpful if, where appropriate, health
professionals inform recipients about what the donation experience is typically
like for most donors (i.e., positive and intrinsically rewarding) and inform, educate and support them through this process (Burroughs et al 2003).

The desire to reciprocate in these recipients was also strong and, given the nature of the 'gift' (i.e., a kidney and 'life' itself), this is perhaps unsurprising. However, despite the unrequitable nature of the gift, the transplant did not cause any problems between donors and their recipients. However, it would appear that a certain degree of gratitude is required from recipients and is, perhaps, an implicit expectation of live donors (Murray 1987, Simmons et al 1987, Schover et al 1997).

The data from this study also support Godbout and Caille’s (2000) contemporary theory that the 'joy of giving' represents a significant, non-material form of reciprocation for live kidney donors and helps to confirm to them that what they did was worthwhile. It is also, perhaps, for this reason that the transplant did not cause any relationship problems in donors and recipients. Nonetheless there is a need for donors and recipients to move on with their lives after transplantation. It would appear that donors have an important role to play in helping to bring this about, by reducing the recipients’ feelings of indebtedness, by, for example, downplaying their actions and not talking excessively about the transplant.

This study also provides a unique insight into the personal dimensions of graft rejection, an area that has been very poorly researched. As this and other studies show, graft rejection is a devastating experience for recipients (Carosella 1984, Streltzer et al 1983, Hudson and Hiott 1986) and their donors. It does perhaps
demonstrate the importance of properly preparing recipients for transplantation and ensuring that they are fully aware of potential complications, such as graft rejection. The findings from this particular aspect of the study generates the question of whether the pre-transplant coping mechanisms used by recipients to deal with the prospect of graft rejection contribute to the feelings of devastation felt by recipients such as R3, if and when, rejection occurs? This study also highlights the importance of providing adequate care and support to recipients and donors post rejection, particularly after discharge. Furthermore, any such care should be offered in a way that increases the likelihood that it would be accepted, if required.

The study shows that the transplant service was, on the whole, positively evaluated by participants and the staff should be commended for this. However, as this and other studies have shown, the service provided to those involved in live transplantation could be improved further (Peters et al 2000). The area that was highlighted by participants as requiring significant improvement was post-transplant follow up care for donors. This has also been highlighted in other studies, as far back as 1994, and does, therefore, indicate that this particular aspect of care does need to be addressed by health professionals (Hilton and Starzomski 1994, Eggeling 1999a, 1999b, 2000). Other areas of service provision recommended for improvement were counselling (informal or formal) and information provision.

11.4 Implications for future practice

- Transplant centres should consider the necessity of providing a dedicated counselling service (formal and/or informal) to donors and recipients to
discuss issues of concern before transplantation. Considering the findings that the interview process was helpful, or even therapeutic, for donors and recipients, it seems reasonable, perhaps, to suggest that they may also find talking to a counsellor beneficial, especially as many requested such a service.

- The pre-transplant work up process for donors should, where appropriate, be of a sufficient timescale to allow them to fully contemplate their decisions.

- Where treatment and care is provided by two separate hospitals, health professionals in each centre should carefully consider their behaviour regarding staff and treatment suggestions in the other, in the presence of patients. Professionalism is required, as well as the recognition that discordance can cause concern and uncertainty in patients.

- Where appropriate, recipients should be encouraged to talk to their donors about the transplant, providing of course they are genuinely happy to proceed with the transplant, so that they can reassure them and facilitate their decision making.

- The onus of requesting organs should, where possible, be removed from recipients. Health professionals should carefully consider how to inform and educate family and friends about the prospect of live transplantation. The media can also help to raise awareness of who can, in theory, donate to whom.

- Follow up care for donors is an area in need of specific improvement.

- In the unlikely event of graft rejection, recipients and their donors should be provided with appropriate emotional care and support and this should also, where appropriate, continue after discharge home. Such care should be offered in a sensitive manner that increases the likelihood that it is accessed by those who require such support. It may also be prudent for centres to consider developing post-rejection follow up, emotional care protocols.

- Prospective donors and recipients must be properly prepared for transplantation and made fully aware of potential complications such as rejection. Live donor information evenings are undoubtedly a significant source of information and support for those considering live transplantation and should, therefore, be offered to all prospective families. However, they should not be the sole source of information. The centre should also consider developing more evidence based written information, particularly regarding pre operative issues and discharge information, to support existing verbal information.
11.5 Limitations of study and suggestions for future research

I believe that the findings demonstrate that this study has achieved its original aims and objectives. However, it is recognised that, as in most research, there are limitations to this qualitative study, which was conducted in one regional renal transplant centre in South-West England. Consequently, the views and experiences of participants in this study cannot be assumed to be representative of all live transplant patients attending other UK transplant centres, although many service provision issues, such as follow up care, have also been reported in other national (e.g. Eggeling 1999a) and international (e.g. Hilton and Starzomski 1994) studies.

The sample size was small (n=22) and non-randomly selected, which limits the generalisability of the study findings to the wider transplant community. The purpose of qualitative research, however, concerns depth of understanding rather than generalisability. Nevertheless, certain aspects of the study findings, such as donors’ decision making, have also been found in other studies (e.g. Simmons et al 1987, Schweitzer et al 2003).

Finally, most families in this study were spousal (n=8) and all participants’ experiences, with the exception of F3 (particularly at 3 months post-transplant), were generally very positive. Caution should be exercised, therefore, in transferring these findings to the experiences of all families undergoing live transplantation, particularly in relation to non-spousal donor-recipient relationships.
Therefore, this work has also raised further questions for future research in this particular area. The rates of live transplantation are likely to significantly increase in the developed world over the coming years, primarily because of the current shortage of cadaveric human organs and the success rate, coupled with relatively low physical risks, associated with the procedure (Olbrisch et al 2001). However, as live transplantation becomes more frequent, studying medical and psychosocial outcomes for donors and recipients becomes essential (Olbrisch et al 2002). Studies need to be prospective and longitudinal and include investigations of:

- The empirical evaluation of routine pre-transplant psychological assessments to explore whether the process is beneficial to practitioners and/or donors and recipients.
- The perspectives of 'significant others' (e.g., spouses) not undergoing transplantation to better understand their experiences of the process.
- The rejection experience, from the perspectives of donors (especially spousal) and recipients, particularly in the context of grief and loss.
- Coping styles used in relation to dealing with potential problems, such as rejection. This could perhaps improve understanding of whether emotion focused styles of coping, such as denial, exacerbates the emotional impact of graft rejection if and when it occurs; or, alternatively, if facing up to potential problems is counter productive and merely causes unnecessary anxiety for something that may never affect them.
- The interview experience for participants involved in other kinds of emotive, qualitative research.

11.6 The research experience: a personal reflection

Before concluding this thesis I would like to briefly reflect on the PhD process. Conducting a doctoral study is demanding and, at times, arduous and eventful, as most PhD holders can probably attest to. This was certainly the case with this study, although the overall research experience was enjoyable, rewarding and extremely educational. As already discussed, I have outlined in some detail how
this study was conducted, the methodological decisions that I made along the way and the problems that I encountered while conducting this research.

For example, not being able to explore the experiences of ‘significant others’, as originally anticipated, due to the relationships of study participants. This resulted in a change in focus of the study, as discussed earlier. However, whilst initially disappointing this helped to serve as an important learning exercise for me and helped me to realise that few studies progress along a straight line. Adaptation and change are often required in many studies.

I also had not anticipated at the outset that any families in this study would suffer an irreversible episode of graft rejection during data collection, primarily because of the high success rate of live kidney transplants, particularly in this transplant centre, in the first year post-transplant. However, whilst this experience was devastating for F3, it helped to illuminate a previously poorly understood aspect of transplantation that has profound clinical and empirical implications and, consequently, this is an extremely important aspect of this study.

I found interviewing participants about emotive issues fruitful, informative, interesting and at times demanding, for me and especially them. I have my primary supervisor, Dr Lowes, to thank for helping me to critically review, refine and develop my interviewing skills. Fortunately, most of the experiences recounted by participants were generally positive, although often emotional. Unfortunately, the three month interview with F3 was harrowing and I actually ran out of tapes to record the interview (each interview lasted well over an hour).
For both D3 and, especially, R3 the experiences were very emotive and for the first time in the series of interviews I felt emotionally drained when I left their house. I suspect that if all of the interviews had been like that those, it would have made the study very emotionally difficult to conduct.

However, that said, I believed that, at the time of these interviews, both D3 and R3 also found having the opportunity to talk about their experiences cathartic. This was subsequently confirmed by them (and other participants) when I interviewed them both for the last time at 10 months post transplant. Consequently, this personally raised the prospect that research interviews could potentially have a cathartic, or pseudo-therapeutic effect on participants, if conducted appropriately and sensitively. However, it also emphasised to me how emotionally demanding interviews can be for researchers and the need, therefore, for appropriate support mechanisms to ‘debrief’.

Having conducted and completed a part time PhD is, I feel, a significant achievement and the process has made a considerable contribution to my personal and professional development. Amongst other things, besides developing essential research skills, knowledge and experience, the PhD experience has also helped me to critically think and work independently. However, having now completed the PhD, perhaps the most important thing that I have realised is that attaining a PhD is the beginning and not the end of an academic career.
Consequently, this work has given me an appetite for further research in this area. My immediate priorities for the future are, therefore, to begin publishing key findings from my study and also to explore suitable opportunities for post doctoral research in this and other related areas.

11.7 Conclusion

I believe this research has helped to illuminate an area that has previously been poorly understood. Participants have provided detailed accounts of their experiences of the live transplant process, before and in the first year after transplantation. They also provided a critical appraisal of the provision of transplant services. Furthermore, the study has also provided a comprehensive insight into the motivations, feelings and concerns associated with donating and receiving a kidney and the impact the transplant had, whether successful or unsuccessful, on donors, recipients and, where appropriate, their families. Data also show that the experiences of participants in this study relate closely to the fundamental dynamics (although occasionally in slightly different ways, due to the nature of ‘the gift’) of the gift exchange process. I therefore propose that this study has answered the research questions and has also advanced knowledge and understanding about the study phenomenon.
References


Harvey (1990) Paying organ donors. *Journal of Medical Ethics* 16, 117-119


UK Transplant (2006d) Number of deceased donors. Personal communication.


Appendix 1: Sources of literature reviewed

Literature informing the introduction, literature review, methodology and much of the discussion chapters of the thesis were obtained from computer databases, hand searches of key journals published up to June 2006 and review of the reference lists of relevant articles obtained from both sources.

Databases searched

CINHAL & BNI (Nursing Literature)
MEDLINE (Medical Literature)
ASSIA, ClinPsych & INGENTA.COM (Psychosocial Literature)

Search terms used were related to the research questions and included (in a variety of combinations):

Gift (not G.I.F.T. – gamete intrafallopian transfer)
Gifting
Live
Living
Related
Organ(s)
Kidney(s)
Renal
Donor(s)
Donation
Recipient(s)
Transplant(s)
Transplantation

Journals searched

A variety of libraries (primarily medical and nursing) were visited regularly between January 2002 and June 2006 to identify new, relevant published work. Because of their potential relevance to the research topic, the following medical, nursing and social science journals were frequently hand searched:
The ‘grey’ literature

In an attempt to locate as many relevant sources of information as possible, including conference proceedings, dissertations and unpublished or non-indexed articles (grey literature), I wrote to several appropriate clinical and academic colleagues for guidance. These included transplant professionals in the South West region of the UK, a transplant psychologist in South Wales, a professor of social anthropology (with an interest in transplantation) in Japan, a post doctoral researcher in social anthropology in Edinburgh university (with an interest in medical anthropology and organ transplantation) and the British Organ Donor Society (BODY) in Cambridge.
Appendix 2: Comments from the Local Research Ethics Committee

23 May 2003

Dear Mr Gill

PROJECT XXXX/XXX: ILLUMINATING THE EXPERIENCES OF PATIENTS AND THEIR FAMILIES IN LIVE KIDNEY DONATION

The XXXXXXXXX Local Research Ethics Committee reviewed your application on 21 May 2003. The members of the Committee present agreed there is no objection on ethical grounds to the proposed study. I am, therefore, happy to give you the approval of the Committee on the understanding that you will follow the conditions set out below.

➢ You do not recruit any research subjects within a research site unless approval has been obtained from the relevant REC.

➢ You do not undertake this research in an NHS organisation until the relevant NHS management approval has been gained as set out in the Framework for Research Governance in Health & Social Care.

➢ You do not deviate from, or make changes to, the protocol without prior written approval of the REC, except where this is necessary to eliminate hazards to research participants or when the change involves only logistical or administrative aspects of the research. In such cases, the REC should be informed within seven days of the implementation of the change.

➢ You should complete and return the standard progress report for the REC one year from the date of this letter, and thereafter on an annual basis. This form should also be used to notify the REC when your research is completed and in this case should be sent to the REC within three months of completion.

➢ If you decide to terminate this research prematurely, you send a report to the REC with 15 days, indicating the reason for early termination.

➢ You advise the REC of any unusual or unexpected results that raise questions about the safety of the research.

This project must be started within three years of the date of this letter.

Yours sincerely

XXX X X XXXXXXX
Administrator
XXXXXXX Local Research Ethics Committee
Appendix 2a: Letter to the Local Research Ethics Committee

Paul Gill

04 May 2004

RE; PROJECT XXXX/XXX: ILLUMINATING THE EXPERIENCES OF PATIENTS AND THEIR FAMILIES IN LIVE KIDNEY DONATION

To Whom It May Concern:

I was granted LREC approval for my study in May 2003 and subsequently started collecting data, through semi-structured interviews, in July 2003. I have now recruited a total of 11 families into the study.

The composition of the families recruited are as follows;
- Husband to wife donation – 3
- Wife to husband donation – 5
- Brother to sister donation – 1
- Mother to daughter donation – 1
- Father to son donation – 1

Because of the large number of spousal donations and single donors and recipients in other family groups I have only been able to recruit two significant other family members into the study. However, due to working commitments of the spouse in Family 11 (father to son) I was unable to interview her pre-donation. I have, therefore, been left with no alternative but to now exclude her from the study. This, therefore leaves me with just one significant other (the husband in Family 4 – brother to sister donation) family member in the study.

I have discussed this matter at length with my PhD supervisor and we both feel that, whilst the views and experiences of this person will be of interest, I will not really be able to make any realistic conclusions based on the experiences of just one significant other family member. We therefore feel that it would be wise to just concentrate on the experiences of donors and recipients only as there simply aren’t enough significant others to interview.

Besides this issue the study is progressing very well and I will, of course, submit an annual progress report form at the end of May. If you require any further details or would like to discuss this matter please don’t hesitate to contact me at the above address or email,

Yours truly,

Paul Gill
Appendix 2b: Additional comments from the Local Research Ethics Committee

13 May 2004

Dear Mr Gill

PROJECT XXXX/XXX: ILLUMINATING THE EXPERIENCES OF PATIENTS AND THEIR FAMILIES IN LIVE KIDNEY DONATION
Amendment number: 1
Amendment date: 4 May 2004

The above amendment was reviewed by the Executive Sub-Committee of the Research Ethics Committee at the meeting held on 7 May 2004.

Ethical Opinion

The members of the Executive Sub-Committee present gave a favourable ethical opinion of the amendment on the basis described in your letter of 4 May 2004.

You should please ensure that exclusion of ‘significant other family members’ does not affect the wording of the patient information sheet. Should it do so, it should be amended appropriately, and a copy forwarded to me for my records, bearing a new version number and date.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting were Dr Xxxxxxx Xxxxxxx (Consultant Anaesthetist) [in the Chair] and Ms Xxxxxx Xxxxx (Research/Audit Nurse).

Management approval

Before implementing the amendment, you should check with the host organisation whether it affects their approval of the research.

Statement of compliance

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

Yours sincerely

XXX X X XXXXXXX
Administrator
XXXXXXXXXXX Local Research Ethics Committee
**Appendix 3: Study information sheet for donors and recipients participating in the study**

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**Information sheet about the study:** “Illuminating the experiences of patients and their families in live kidney donation.”

Live kidney donation is a successful way of treating many people with chronic kidney failure. However, the transplantation process can be emotionally demanding and so may affect the lives of the donor, recipient and other close family members. Even though families considering a live kidney donation are faced with a number of important decisions no clear guidelines are available to help them through the experience. It is unclear, therefore, whether the care, information and support currently provided to those involved in live donations adequately meet their needs.

This study is being carried out to give us a better understanding of the experiences of the live donor, recipient and their immediate families (e.g., spouse) throughout the transplantation process – to explore how families cope with the process and to identify possible areas of worry or concern. Knowing more about the experiences of families involved in live donations may help healthcare professionals to improve the care, information and support provided to families.

Some families involved in live kidney donation are being asked to take part in this study. The study will involve a series of tape-recorded interviews with the donor, recipient and their immediate family members (e.g., spouse). These interviews will be conducted by Paul Gill, the researcher carrying out this study, and can be undertaken in your house or somewhere more convenient for you. All interviews will be conducted separately with each person (not as a group) and should last 30-45 minutes. They will take place just before donation and on 2 separate occasions in the first year after donation.

Participation in this study is voluntary and if you do agree to take part the information you provide will be confidential (unless, of course, you disclose information of an illegal or unusual nature – e.g., a desire to harm yourself or others). All tapes and transcripts will be coded so that your identity will be protected. The information you give will only be used for research and you will not be identifiable in any subsequent publication of the research findings. You may stop an interview, or withdraw from the study, at any time, without it affecting your, or your family members’, care now or in the future. This study is also entirely separate from your or your family members’ care. It should also be emphasised that whether or not you decide to take part in this study, the care given to you or your family member by the transplant team will not be affected in any way.

Those who agree to take part in the study will need to give their consent by signing the attached consent form. We do hope that you will take part in this study. If you have any questions or concerns or would simply like some further information, please contact Paul Gill at the above address, telephone number or email.

Paul Gill
Research/PhD student, University of Wales College of Medicine, Cardiff.
Appendix 4: Consent form for donors and recipients participating in the study

CONSENT FORM

Title of study: "Illuminating the experiences of patients and their families in live kidney donation"

Name of Researcher: Paul Gill

I confirm that I have read and understood the information sheet given to me regarding the above study. I agree to participate in a series of tape-recorded interviews in my home or at a mutually agreeable location.

I understand that my participation in this study is voluntary and that I am free to stop an interview, or withdraw from the study, at any time without my treatment, care or legal rights being affected.

I also understand that the content of the interviews will be confidential and that I will not be identifiable in any subsequent publication of the research findings.

I agree to take part in the above study.

Name:

Signature:

Date:
Appendix 5: The interview schedule

Live donor – Pre Transplant interview

Demographics:

- Age
- Gender
- Marital status
- Social circumstances (e.g., who do they live with)
- Occupation
- Relationship with recipient
- Date, time and location of interview
- Date of transplant
- NHS Consultant & GP details

Interview themes:

- Can you describe your experience from the time you discovered that your relative/friend needed a kidney transplant?
- Can you describe your relationship with your relative/friend since you offered to donate your kidney to them?

Live donor – 3 months post transplant

Interview themes:

- Can you tell me about your experience immediately leading up to the transplant?
- Can you tell me about your experience following the transplant?
- Can you describe your relationship with your relative/friend since the transplant took place?

Live donor – 10 months post transplant

Interview themes:

- Can you tell me about your experience since the transplant took place?
- Can you describe your relationship with your relative/friend since the transplant took place?
Recipient – Pre Transplant interview

Demographics;

- Age
- Gender
- Marital status
- Social circumstances (e.g., who do they live with)
- Occupation
- Relationship with donor
- Date, time and location of interview
- Date of transplant
- NHS Consultant & GP details

Interview themes;

- Can you tell me about your experience since you discovered that you needed a kidney transplant?
- Can you describe your relationship with your relative/friend since they offered to donate their kidney to you?

Recipient – 3 months post transplant

Interview themes;

- Can you tell me about your experience immediately leading up to the transplant?
- Can you tell me about your experience following the transplant?
- Can you describe your relationship with the donor since the transplant took place?

Recipient – 10 months post transplant

Interview themes;

- Can you tell me about your experience since the transplant took place?
- Can you describe your relationship with your relative/friend since the transplant took place?
Appendix 6: Coding Framework for interview data

Coding framework for pre-transplant interviews:

- **Discovery**
  - Diagnosis and discovery of chronic renal failure
  - Causes of renal failure
  - Impact of diagnosis on recipients and donors (e.g., grief, shock and denial)
  - Acceptance of condition and need for dialysis and/or transplantation

- **Effects of illness on life and lifestyle**
  - Physical effects of condition (e.g., lethargy, irritability, itching, altered sleep patterns and lack of energy)
  - Psychological effects (e.g., depression and anxiety)
  - Social effects (e.g., loss of employment, lack of social life, loss of hobbies and inability to go on holiday)
  - Impact on family (e.g., role change, reduction in family activity)

- **Treatment issues and options**
  - Drug, fluid and diet regime associated with renal failure and impact on life and lifestyle
  - Dialysis regime – fear and loathing of, perceptions of dialysis units and patients
  - Acceptance of dialysis and incorporation into life and lifestyle
  - Impact of dialysis on life and lifestyle (physical, psychosocial)
  - Complications and problems with dialysis
  - Recognition and acceptance of transplantation as best treatment option

- **Coping**
  - Coping mechanisms used to cope with illness and deteriorating health (defiance, getting on with life, remaining positive, trying not to worry, avoid dwelling on things that they could no longer do, build life around condition, breaking the process down into stages)
  - The transplant as a source of hope and optimism (but also concern – e.g., the prospect of graft failure)
  - Cross that bridge (e.g., avoidance)

- **The decision making process**
  - The process involved in deciding to donate (donors) and deciding to accept the offer of a transplant (recipients)
  - Donors – instantaneous, voluntary, free from pressure, relatively easy, didn’t feel brave or heroic
  - Factors that complicated donors’ decision making (concerns regarding genetic match, the possibility that a daughter may also need a kidney)
  - Deliberation of decision making (D4)
  - Determination to donate
  - Reasons for donating (all donors, spousal donors)
  - Recipients - Best treatment option for recipients (and their families)
  - Grateful but concerned for donors’ wellbeing
Accepted after discussing the matter with donor
No pressure exerted on donor to donate
Couldn’t ask for a kidney
Would only accept a kidney from certain donors (e.g., if given ‘conditionally’)

➤ **Feelings and concerns about the impending transplant**
Feelings about the impending procedure
Recipient’s feelings about the donor’s offer to donate
The transplant as a source of hope and optimism
Concerns regarding the transplant (finding something wrong, postponement, donor’s/recipient’s well being)
Recipients reassured about transplantation by donors and health professionals
Family members’ concerns
Fear of rejection or failure of the transplant
Concerns about the operation and recovery (e.g., pain, urinary catheters, follow up care, support from GP)

➤ **Donor-Recipient relationships**
Recipients grateful to donors for donating
No change in donor-recipient relationships
Improvement in donor-recipient relationships

➤ **Transplant service issues**
General praise for the service and staff
Lack of support for non-donor sister (D4)
Concerns regarding service links and support for GPs (D5)
Other issues (clinics, ULTRA process)
Information provision and needs (generally happy, further need for leaflet/books, more information needed on certain topics, specific concerns)
Live donor information evenings (major source of information, informative and beneficial, meeting previous families, concerns regarding distance, timing, sufficient families, balance of information and families invited to speak, not for everybody).
Need for further support or a dedicated counsellor
Shared hospital care (communication break down, conflict between clinicians, effects on patients)
Coding framework for 3 month post-transplant interviews:

- **Getting ready for the transplant**
  - Preparing for admission to hospital
  - Health problems experienced by some recipients
  - Feelings about the impending transplant
  - Operative concerns (donor/recipient well being, pain, the operation, fear of postponement, fear of not being able to go through with it)
  - Concerns about the transplant (rejection/failure)
  - Feelings about each other at the time of surgery

- **The operation and post operative recovery**
  - Operative experiences (uneventful and problematic – D11)
  - Feelings and concerns regarding operative complications (F11)
  - Post-operative period (pain, discomfort, analgesia problems, recipient concerns about donors)
  - Post-operative complications (nausea and vomiting, wound problems, UTIs, acute graft rejection, ureter problem – R9)
  - Feelings and concerns regarding graft rejection

- **Life after the transplant**
  - Recuperating after discharge
  - Complications (wound problems, weight gain and acute rejection)
  - Getting back to normal
  - The impact of the transplant on recipients’ lives (improved health, gardening, driving and exercise)
  - The impact of the transplant on the lives of other family members (improved lifestyle)

- **Feelings and concerns about the transplant**
  - Recipient’s feelings (happy, grateful)
  - Donor’s feelings (happy, proud, no regrets, not brave or heroic)
  - Time to move on
  - Fear of rejection

- **Donor-recipient relationships post transplant**
  - No relationship problems
  - Relationships improved or remained the same
  - Potential for the transplant to alter the tenor of the relationship between donor and recipient (all ensured that relationships didn’t change)

- **Service issues**
  - Generally happy with care and support provided
  - Beneficial being kept in the same ward areas as each other whilst in hospital
  - General service concerns (appearance of ward, short staffed, analgesia pump problems, noise levels, care from physiotherapists and ULTRA application)
Information –
Generally happy with level and content of information
Concerns regarding timing of pre-operative information
Live donor information evenings (major source of information, F4
concern regarding balance of information presented)
Discharge information needs and areas for improvement

Follow up care –
Recipient’s perspectives (happy, concerned waiting for blood results)
Donor’s perspectives (some happy with level of follow care, most
unhappy and felt neglected)

Family 3’s experiences

➢ The impact of rejection
Deterioration in renal function
Medical investigations and aggressive therapy to correct the problem
(biopsies, heparinastion, immunosuppressant therapy)
Removal of transplanted kidney
Physical impact of rejection (weight loss, lethargy)
Psychosocial impact of reaction (depression, suicidal thoughts, treatment
from GP, effects of rejection of relationship)

➢ Treatment issues and options
Necessity for haemodialysis (physical and psychosocial impact of,
problems with HD)
Necessity for CAPD (easier and more bearable, constant reminder of
graft failure)
Transplantation still the best long term treatment option (feelings and
concerns about the possibility of another transplant)

➢ Coming to terms with rejection
Moving on with life
Taking things one day at a time
Another transplant as a source of hope and optimism
Donor-recipient support for each other
Donor’s concern regarding how best to support his wife
Regaining personal control over life

➢ Service issues
Generally happy with care and support (and supportive of each other)
R3’s perception that some staff found supporting them difficult through
the process
Critical of emotional care and support post-discharge
Well informed about rejection and treatment issues
Concern regarding the balance of pre-operative information (particularly
regarding potential complications such as rejection – R3)
Coding framework for 10 month post-transplant interview

- **Getting back to normal**
  Health and fitness levels, resuming ‘normal activities’ (e.g., work and exercise)
  Improvements in recipients’ lives and lifestyle (excercise, work, making plans)
  Improvements in family life (social life together)

- **Post-transplant complications**
  Weight gain and other complications (e.g., UTI’s)
  Acute graft rejection
  Wound problems (shape, discomfort)
  Ureter problems (requiring stents – D9)

- **The impact of the transplant on donors and recipients**
  Recipients’ feelings regarding transplant, improvements in the lives and the donor’s actions
  Donors’ feelings regarding recipients’ improved health and donating
  The potential for relationship problems and ‘indebtedness’
  Donor-recipient actions to maintain ‘normal’ relationships
  Donors’ feelings regarding their actions
  The need to ‘move on’

- **Concerns for the future**
  The need to maintain personal health
  Child birth (D6)
  Graft failure/rejection
  Ureter problems (F9)

- **Service issues**
  Generally happy with the service
  The desire to ‘give something back’
  Scanner issues (D9)
  Care from physiotherapists whilst in hospital (D11)

  Information –
  Generally happy but more information required regarding anti-rejection medication
  Importance of live donor evenings to prospective families

  Follow up care –
  Recipients’ perspectives (happy, increased feelings of personal control now frequency of follow up was decreasing)
  Donors’ perspectives (insufficient)

**Family 3’s experiences**

- **Getting back to normal**
  Donor wound problems
Recipient problems (Anaemia, CAPD related infections, MRSA)
Impact of rejection and continuing problems
Regaining personal control over life
Effects of improved health on F3
Importance of making the most out of life
Difficulty in support wife (D3)
Effects of rejection on relationship

➢ **Treatment issues**
  Preference for CAPD
  No regrets about transplantation
  Transplant still the best long term treatment option (although still concerns R3 due to previous experience)

➢ **Service issues**
  Generally happy with care and support
  A need to improve post-discharge information
  Questions regarding preparedness for rejection, due to balance of pre-transplant information (R3)
  Concerns regarding lack of post-discharge emotional support
Coding framework for pre-transplant interviews:

Examples of interview extracts from which coding keys arose:

“Well I was diagnosed as having poly-cystic disease when I was... 36. I had just miscarried and it was at that point that the polycystic disease was diagnosed. And nobody really took much notice after the initial kind of diagnosis. I was not looked after at all, I just went off and carried on with the rest of my life, had another child. And as far as I was concerned, that was it really. And although I’m a medical professional I never really looked into it, because nobody really explained to me that I should.... So eventually, about 6 or 7 years ago now... I had an episode of abdominal pain and went to my GP. My GP thought I might have cholecystitis so I was then referred to see a GI Consultant, who thought I should be seen by a nephrologist, which was when I saw Prof XXXXXXXX for the first time… and it was him who said to me “Of course you do realise that your renal function is going off and you’re going to have to have a kidney transplant, or go on dialysis or whatever in due course.” And at the time it came as an absolutely appalling shock. I was, you know, devastated really.”
(R3, wife, 1st interview).

“I was working full time in a managerial position and I had to give up work, and I’m now on disability living allowance. So it’s kind of letting go of working of the responsibility and I found that, at that time, intensely difficult. I didn’t want to give up work. I fought to stay but I wasn’t able to do my job, so that had to go. And also I play the double bass but I haven’t had the stamina to do that or you know to play in orchestras and bands, where I had a social life.

And before I went on dialysis I was probably sleeping 20 hours a day. And with the liver transplant there was no illness and I just recovered. I’ve never ever experienced anything as debilitating as the kidney... And I mean I go to bed at 6 or 7 o’clock at night... And so my lifestyle has...”
(R4, sister, 1st interview).

“I didn’t have to think about it.... it’s hard to explain really............. It was just a natural thing. I didn’t sort of think shall I do it or not it was just yeah I’ve got 2 take one. I’ve always been there for the kids no matter what they had or what they’ve done etc.

I feel now exactly the same as then, you know. I’m not worried about it, I’m not concerned about it. I know it’s going to happen and that’s about it really. I just want to help him get better.”
(D11, father, 1st interview).

Coding Keys:
- Discovery
- Effects of illness on life and lifestyle
- The decision making process
Coding framework for 3 month post-transplant interview

Examples of interview extracts from which coding keys arose:

“Well leading up to it was really getting ready to go in. It was almost like going on holiday (laugh), pack all the bags and everything. It was all a bit strange because when we came out of hospital we were having a charity house in Westbury so it was organising about bedding, getting that to our daughter’s place and so on. So that was all in a whirl. We got someone to take us up to the hospital and in we went and XXXXXXXX got her bed, I stayed with her for a while then I stayed at a hotel nearby, went out for something to eat and so on. Then Sunday was there and it was my turn and went into hospital and I was trying to watch the Grand Prix (laugh) and they were saying XXX come and have this or that done, and it was such a whirl. And then Monday morning was there, I even slept well Sunday night, it didn’t sort of bother me. We were very lucky that in our ward we had 2 other people who were also quite extrovert and happy go lucky so we had a good gang altogether.”

(D1, husband, 2nd interview).

“After the anaesthetic I was sleeping for about 3 days and I was very bilious and sick and everything. But after the 3 days I started to feel better and it was fine... my head felt better, you know, I could think clearer.... That muzzy zombie feeling was going. I still felt very weak obviously and I just thought I was more relaxed because I thought well it’s all over now (laugh).”

(R2, wife, 2nd interview).

“At the time, when I was in hospital, it was dreadful. It was like a bereavement almost.... Part of that I think is to do with the fact that you are in an alien environment and no matter how nice people are there is no privacy.... It’s hard coming to terms with something like that in a ward full of other patients, a lot of whom have had successful transplants. The worst thing was, I don’t begrudge them at all, but there were people on the same ward who’d come in after me, had transplants and were going home and were fine. And there was me with everybody talking about me in the corridor and I could hear it, and that was horrid. That was really bad.

“Once I’d come home....... when I was an in-patient I thought right I’ve got to get through this. The only way to get through this is to get through it and I’m not going to break down and I’m not going to make a fuss, I just want to get out. And I focused all my efforts on going home basically because I didn’t want to be there anymore. But when I came home, although it was much better away from the hospital and back in my own place I did get very depressed... but that’s passing. After Christmas I picked up a lot.”

(R3, wife, 2nd interview).

Coding Keys:
- Getting ready for the transplant
- The operation and post-operative recovery
- The impact of rejection
- Coming to terms with rejection
Coding framework for 10 month post-transplant interview

Examples of interview extracts from which coding keys arose:

"I don’t know. Probably everybody with a transplant feels that it could not work. I think in the first year or two you are in quite early days really. I think that’s always at the back of your mind that it won’t work and you’ll be back on dialysis. I think that’s my only concern really.”

(R8, daughter, final interview).

"I think it’s quite easy to forget the enormity of what giving... of what he decided to do. The courage.... It still doesn’t take away that enormous gamble that he took, and it was a gamble, I felt that if things had gone wrong or if it hadn’t worked, he would have... and maybe it might have disadvantaged his health. I just feel like lifeboat men go out and risk their lives. I would like to think that I would have had the courage to do that for someone, but to actually have gone through with it I think is....

I know I’ve been to reunions and some of the donors shrug it off, oh well (shrugs), maybe that’s how they feel but I still think it’s an incredible thing to do. It involved enormous courage and guts. With Xxxxx especially because he hadn’t had any previous illness or experience with hospitals, or physical pain. It’s something almost beyond belief.

The fact that he’s had a good year and is really well and he’s accepting what he’s done. I think if it had adversely affected him I would have very much regretted it, so it has absolved me a bit I suppose...... because I know initially he was very much not wanting to, whereas my sister really wanted to do it. For her it would have been much more of a breeze but for Xxxxx it was much more of an issue.

He’s come out of the experience very well and because of his lean on it and attitude that’s what has really helped me. I think on reflection maybe he was the right person because he’s in no way at all made me feel guilty about it or.... He’s very humble and unassuming. You can’t thank someone enough but there’s no obligation from him, no pressure or anything like oh for God sake Xxxxx look what I’ve done for you. He’s just always... continually pleased and excited for me and that’s great. That’s great for my mind because I think, Christ he did that for me. I’m really going to work hard and make something of it, yeah.

I think that maybe there is a potential for me and people like me to feel beholden to the donors for what they have done. But I think it’s the donor’s attitude and they way they behave with you after the transplant that allows you to get on with your life without feeling.... Well without feeling indebted to them. I think like... because most donors, I think, don’t feel that what they have done for you is particularly brave or heroic or exceptional in anyway, and they don’t expect us to feel beholden to them, allows us to move on without feeling awkward or... feeling that you owe them something for the brilliant thing that they’ve done for you.”

(R4, sister, final interview).
"No looking back it’s still quite recently but I suppose it was around the first day I went back to work. Originally I wanted to go back 3 or 4 days a week and the occupational health people wouldn’t let me. So I had to do it very gradually and that was like a milestone, you know. It was like I’m not a sick person any longer I can pretend to be a normal person. So there was that, that was quite important to me.

Then within about 3 weeks of going back to work XXXX and I had a holiday. We had a week in north Devon and a week in Cornwall. The week we were in Devon we had booked to stay in a holiday cottage, which had footpaths and cycle ways nearby, before my transplant went wrong we always walked and cycled a lot. To cut a long story short we went there and we had a week of glorious weather and I cycled for about 4 days, over 130 miles…. I thought to myself, we were cycling along one day with lovely scenery and it was a lovely day, and I thought thank god I didn’t kill myself (laugh).

When I came back I thought well if I can cycle 130 miles it doesn’t really matter whether I’m on dialysis or not because, well I don’t want to cycle that every week, but it was a big psychological boost. After that I thought well I can still enjoy my life. XXXXX and I can still do things that we want to do, the thing is to do them while we can still do them and nor sort of hang about thinking oh well I won’t cycle until I’ve got a kidney transplant, because I’m a fit person and I’ve got dialysis – bugger that. All right I’m a fit person and I’m on dialysis but why should it stop me from doing what I want to do”?

(R3, wife, final interview).

Coding Keys:

- Concerns for the future
- The impact of the transplant on donors and recipients
- Getting back to normal