Psychosocial Outcomes in Living Kidney Donors: Predictors and Processes

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Psychosocial Outcomes in Living Kidney Donors: Predictors and Processes

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Thesis submitted to King’s College London, University of London for the degree of Doctor of Philosophy (PhD)

School of Medicine

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Abstract

Living kidney donation, the gift of a kidney from one individual to another for the purposes of transplantation, is a practice which goes against some of the most fundamental principles of medical ethics. Traditionally, it has been justified on the basis that the donor will benefit psychologically from donating, however data are limited that demonstrate this to be the case.

The aim of this mixed-methods thesis was to explore the psychosocial aspects of living kidney donation, and to determine whether both positive and negative physical and psychosocial outcomes could be predicted. A qualitative study using in-depth interviews was conducted to identify the pertinent issues and to generate hypotheses. This included 23 pre- and post-operative living kidney donors. It was followed by a longitudinal quantitative study which utilised a number of both validated questionnaires and purposely designed questions to prospectively measure different psychosocial and transplant factors pre- and post-operatively. One-hundred living kidney donors participated.

Additionally, a wound healing study was conducted to determine whether pre-operative psychological factors had an effect on physical recovery. The surgical wounds of 58 living kidney donors were scanned using high-resolution ultrasound to see whether rates of wound healing were influenced by stress, personality and optimism.

The final study explored unspecified kidney donation; a practice whereby individuals choose to donate a kidney to a stranger on the waiting list. As these donors do not know the recipient of their donation there is a concern that psychosocial outcomes in this group may differ to outcomes in specified donors (those donating to someone they know). A national consecutive sample of unspecified kidney donors was recruited to a retrospective questionnaire study. Questionnaire responses from 148 unspecified donors were compared with 148 specified donors; thus making it the world’s largest study of unspecified donation.
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Stress predicts the trajectory of wound healing in living kidney donors as measured by high-resolution ultrasound.

Maple H, Chilcot J, Lee V, Simmonds S, Weinman J, Mamode N.
Brain Behavior and Immunity 2015 Jan; 43C: 19-26

Motivations, outcomes, and characteristics of unspecified (nondirected altruistic) kidney donors in the United Kingdom.

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Appendix 9: Paper: Motivations, outcomes, and characteristics of unspecified (nondirected altruistic) kidney donors in the United Kingdom.
Prelude
Thesis Structure

This thesis outlines an in-depth assessment of the psychosocial aspects of living kidney donation. Following a discussion of the moral and ethical issues pertinent to living kidney donation, an outline of the UK living kidney donation guidelines is provided. The available literature on psychosocial outcomes after living kidney donation is then presented and reviewed. Four studies then follow.

Study one is a qualitative in-depth interview study of pre- and post-operative living kidney donors. It was conducted with the primary aim of identifying which donor-related factors may be associated with a positive or negative psychosocial outcome following living kidney donation. The results of this study were analysed using framework analysis. They provided guidance for the design of the second study and generated the main hypotheses.

Study two is a longitudinal assessment of psychosocial outcomes in a sample of one hundred living kidney donors. Participants completed questionnaires at three time points – once before donation and at three and twelve months after donation. This study allowed an assessment of living donors prior to surgery and examined the changes in different psychosocial measures over the first year after donation.

Study three is a wound healing study. Psychological stress and personality have been implicated as factors that influence the speed of wound healing; however the available literature on surgical patients is limited. As living donors are healthy individuals undergoing major surgery they provide a unique patient group on which to further investigate the impact of stress and personality on wound healing. A subsample of living kidney donors recruited to study two had their wounds scanned with a high-resolution ultrasound machine. Images were correlated with pre-operative questionnaire scores to determine whether psychosocial factors were associated with wound healing and physical recovery.

Study four is a retrospective study of psychosocial outcomes in unspecified donors; individuals who donate to a stranger on the waiting list. It was conducted in collaboration with NHS Blood and Transplant. A national consecutive sample of unspecified kidney donors was recruited to a questionnaire study. Responses from
148 unspecified donors were compared with 148 specified donors, who were recruited locally, to see whether there was a difference in psychosocial outcomes between the 2 groups.

The thesis concludes with a summary and recommendations for both future research and clinical practice. Papers associated with the thesis appear in the appendices.
“...as physicians motivated and educated to make sick people well, we make a basic qualitative shift in our aims when we risk the health of a well person, no matter how pure our motives...”

Dr. Joseph Murray, 1966
Chapter 1
An Introduction to Living Kidney Donation

Living kidney donation is the gift of a kidney from one individual to another for the purposes of transplantation. Living donor kidney transplantation is considered the optimal treatment for people with end-stage renal failure (ESRF) principally due to superior rates of graft and patient survival when compared to alternatives such as dialysis and an organ from a deceased donor (Barnett and Mamode, 2011). The success of living donor kidney transplantation has resulted in living donor nephrectomy becoming a routine surgical procedure which is now performed across the world and on over 1000 occasions across the UK each year (NHS Blood and Transplant, 2013).

Living kidney donation has played an important part in the history of organ transplantation, which in the early years was troubled by technical and scientific challenges such as how to anastomose blood vessels together, how to procure and preserve organs and how to overcome the innate complexities of the human immune system (Watson and Dark, 2012). Following many years of experimental research the first successful human organ transplant took place in Boston, Massachusetts in December 1954 by Dr Joseph Murray (Merrill et al., 1956). This was a living donor kidney transplant performed between two monozygotic (identical) twins. Rejection of the transplanted organ was prevented by their identical genetic makeup and the recipient went on to survive a further eight years after the transplant took place (Jonsen, 2012). This first transplant marked the beginning of the era of transplantation which, following the development of organ retrieval techniques and improved immunosuppressive therapy, has evolved from the extraordinary to the routine.

The psychosocial aspects of living kidney donation have been debated alongside the ethical issues since the very first living donor transplant took place. Dr Murray himself acknowledged that he had undertaken a “great deal of soul searching” prior to performing that first transplant (Murray, 1966), principally due to the morally questionable act of performing a surgical procedure on an individual for the principal physical benefit of another. In order to contextualise the guidelines and available literature on living kidney donation it is essential to understand the pertinent moral and ethical issues that underlie the practice.
Ethical challenges in Living Kidney Donation

Living kidney donation goes against the fundamental principle of medical ethics - *primum non nocere* (above all, do no harm). Although many ethical theories are applicable to transplantation, including paternalism, utilitarianism and deontology, living donation has primarily been discussed within the context of the principlist theory of bioethics devised by Beauchamp and Childress (Beauchamp and Childress, 2009). This theory contains four principles - autonomy, justice, beneficence and non-maleficence. Although this approach is not perfect and is not without its critics it provides a working set of tools that are used every day in transplantation and across modern health care (Lawrence, 2007), and is therefore the ethical theory that will be outlined here.

The principle of autonomy states that an individual has the right to make their own choices and, within the context of healthcare, this translates into the principle of informed consent. Informed consent requires that, in the presence of mental capacity, a patient must be informed of the nature, risks and probable outcomes of an intervention prior to giving their consent. The principle of justice can be summarised as the “moral obligation to act on the basis of fair adjudication between competing claims” (Gillon, 1994) and, for example, requires healthcare professionals to treat people equally and act fairly when distributing goods and services.

The principles of beneficence (to do good or further the patient's interests) and non-maleficence (to avoid or prevent harm) are commonly discussed together. It is conflict between these two principles that is commonly the cause of ethical debate as it is often the case that a particular test or treatment will cause some degree of harm before a benefit is seen. The debate between these two principles is also commonly referred to as the 'best interests' argument, which further reflects the need to strike a balance between harm and benefit. Although these principals can be discussed individually, in practice they invariably overlap and are more frequently considered alongside one another.

It follows that one of the main criticisms of the principlist theory is that no single principle takes clear priority. This is not generally an issue when a patient and their healthcare team are in agreement about the best course of action, such as in a case of appendicitis, as all four principles can be satisfied. In this instance, there is an obvious potential source of harm (the inflamed appendix) and both surgeon and patient are in
agreement that removal of the harm is the best course of action. This is both the beneficent and non-maleficent thing to do as it eradicates the harm and helps the patient get better. The harms caused by surgery (e.g. pain and scars) are justified by the longer term benefit to the patient. The patient exercises their autonomy by providing informed consent to the procedure and the surgeon satisfies the principle of justice by treating the patient as he would any other with appendicitis; by offering the same operation and providing the same supportive care.

Difficulties in using a principlist approach arise when there is conflict between the principles or where it is unclear what is in the patient's best interests, such as when the benefits of a particular treatment are unknown or disputed. Difficulties also arise when a patient and their healthcare team disagree on what course of treatment should be undertaken. Living kidney donation necessitates an even more challenging discussion as the harms and benefits being discussed involve two individuals, rather than one, and the principal beneficiary is different to the person on whom the harm is being inflicted.

When addressing the four principles individually, the principle of justice is the only one that is easily satisfied within living donation. The existence of national guidelines in the UK (devised following a review of the available literature on living donor outcomes) (British Transplantation Society, 2011) helps clinicians treat donors equally before, during and after donation by subjecting them to almost identical tests and appointments. One can extend the principle of justice further by looking at the implications of living kidney donation on the wider population. Living kidney donation provides a better use of medical resources by freeing up a space on the deceased donor waiting list and by providing less competition for deceased donor organs, which are a finite resource. In addition living kidney donation decreases the financial burden of dialysis and allows resources to be redistributed.

Beneficence, non-maleficence and autonomy are much more difficult to address and equilibrate. Put simply, when a living kidney donor consents to surgery they are agreeing to suffer an obvious physical harm with no counterbalancing physical benefit for themselves. In order for the harm to be offset there must be a psychosocial benefit, otherwise the harm cannot be justified. As will be discussed further in chapter two, the psychosocial harms and benefits of living kidney donation are not as extensively
researched as the physical harms and therefore the principles of beneficence and non-maleficence are very difficult to balance.

Adding to the complexities of this situation is the principle of autonomy. Once an individual has been provided with information about the risks of donor surgery and has been told that there is no physical benefit, the principle of autonomy states that that individual has the right to make the decision to donate even if their healthcare team are in disagreement. However, it is not uncommon for some potential donors to be considered unsuitable for donation due to the increased risks of physical and psychosocial harm. An element of paternalism therefore comes into play. There is an extensive literature on the ethical aspects of living kidney donation and it is evident that the ethical dilemmas created by the principlist approach to medical ethics have troubled the transplant community for many years. It is also argued that a donor is unable to make a truly independent informed decision, simply because the procedure is considered life-saving and therefore there is no real choice but to donate (Tong et al., 2012a).

The best interests argument is, in part, assisted by the large amount of research that has been conducted into the physical harms of living kidney donation. These studies help quantify the harm caused by donor surgery and provide supportive evidence about who can safely donate with minimal long-term physical repercussions. As well as aiming to address the maleficent aspect of living kidney donation, these studies also assist the principles of autonomy and justice. They provide information for donors to help them make an informed decision and also contribute to national guidelines so that donors can be treated equally across different centres. As mentioned above, factors relating to beneficence are relatively under researched (Allen et al., 2014).

Research into living kidney donation can be crudely divided into two categories. The first includes those studies assessing the physical aspects of living kidney donation. These studies dominate the literature and share a common aim of trying to reduce the physical harms caused by surgery. These data have helped establish guidance on how donors should be selected, which surgical technique should be used to remove the kidney and how donors should be cared for once they have donated. Rather than discuss these studies in-depth, a summary of the current UK living kidney donation guidelines will be outlined below with references to relevant papers as indicated. The second category of studies includes those considering the psychosocial aspects of living
Living Kidney Donor Evaluation

The primary aims of the living kidney donor evaluation process are to ensure the suitability of the donor and to minimise the risks of donation. The evaluation of potential donors is carried out according to an evidence-based protocol which involves a series of assessments and investigations. The aims of these are to identify the contraindications to donation and the presence of unreasonable medical risks (British Transplantation Society, 2011). This process is organised by a living donor coordinator who is responsible for facilitating the evaluation process. The stages of evaluation are outlined below.

In the UK it is possible to make either a specified or unspecified living kidney donation. Specified donation (also known as “directed donation”) is where an individual donates to a “specific, identified recipient with whom they have a genetic or pre-existing emotional relationship” (Human Tissue Authority, 2013). This can either be a direct donation (where the kidney goes from the donor straight into their identified recipient) or via a paired or pooled donation. Paired and pooled donation takes place on occasions where donor-recipient pairs are either incompatible or a better match is preferred. Donor-recipient pairs are matched with one or more other donor-recipient pairs in the same situation through the National Living Donor Kidney Sharing Scheme and the donor organs are then swapped. When just two pairs are involved it is referred to as a paired donation and where more than two pairs are involved it is referred to as a pooled donation (Human Tissue Authority, 2013). Unspecified donation (otherwise known as non-directed altruistic donation) is where an individual donates to someone who they do not know.

On presentation to a transplant centre a potential living kidney donor undergoes a blood test to confirm that they are a compatible donor to the intended recipient. On occasions where the donor is not compatible with the recipient, discussions are held as to the best course of action. Options include finding another potential living donor, being listed on the deceased donor waiting list or entering into the kidney sharing scheme as discussed above. Should the pair not be matched within the sharing scheme an incompatible transplant is also a possibility. These transplants are a last resort in
the majority of cases as they carry higher risks and require a more complex immunological plan prior to the transplant taking place.

Once a donor has entered into the workup process a brief medical history, aimed at identifying major contradictions to donation, is elicited and routine blood and urinalysis tests are performed. The rationale for this is to eliminate unsuitable donors early before more invasive and expensive tests are performed and to ensure that the intended recipient would be able to receive the kidney from that particular donor. Assuming that the results are acceptable, a living donor co-ordinator facilitates an initial discussion, which involves a conversation about the living donation process, the risks of surgery and the recovery process. This ensures that the donor is made aware of the details of the donation process and is able to give informed consent. In the case of multiple potential donors, the co-ordinator will help identify the most suitable donor, accounting for possible physical and psychosocial factors. This process ensures that only one donor undergoes further testing, thereby saving money, time and minimising harm to those who will not go on to donate.

A full assessment is undertaken by a nephrologist and a transplant surgeon who elicit a detailed medical and surgical history from the donor. The aim of this is to determine whether there are any potential contraindications to donation. Of particular importance are symptoms indicative of underlying kidney disease, such as blood in the urine, and conditions that are associated with the development of kidney disease, such as diabetes and hypertension. A previous history or symptoms of chronic infections, ischaemic heart disease and cancer are also important alongside many others. Although none of these are an absolute contraindication to donation, additional investigations and treatments may be necessary before a donor can be declared fit to donate. A detailed physical examination of the donor is performed to assess for potentially undiagnosed pathologies and also to permit planning for surgery. Again, the aim of such in-depth assessments and examinations is to minimise harm to the donor as much as possible.

A number of medical tests are routinely performed including urinalysis, blood tests, virology and infection screens, cardiac investigations (i.e. electrocardiography) and radiological examinations, such as a chest x-ray. A detailed assessment of kidney function is also performed. This is to ensure that the donor has no underlying kidney disease and that they will have sufficient kidney function after donation, such that they
will remain in good health and at a low risk of developing end-stage renal failure. Additionally, it is important to ensure sufficient kidney function in the recipient. The guidelines, which are evidence based, provide cut off values for each of these tests and for certain donor factors (e.g. age and body mass index).

Radiological tests determining the anatomy and appearance of the kidneys are performed simultaneously. These do not only determine whether the kidneys are healthy but also provide vital anatomical information which is crucial for both the removal and implantation of the kidney. Kidneys with single blood vessels are preferred as they are easier to remove and transplant. It is important that this anatomical information is available before the surgery commences so that no accidental damage to the kidney occurs at the time of donation. The size of the kidneys is also important and where they are significantly different in size, a split function isotope scan is performed to determine what proportion of the donor's renal function is attributable to each kidney. The kidney with the poorer function is then selected for donation, irrespective of the vascular anatomy. The donor will undergo an ultrasound in the first instance, which is followed by a more invasive, detailed assessment by a computerised tomography scan (CT scan) or an angiogram.

A further mandatory stage within the workup process is the independent assessment. This is usually completed once the donor has been passed as medically fit to donate. Under the Human Tissue Act 2004 any potential donation of a solid organ or part of a solid organ for the purposes of transplantation must be assessed by an independent assessor (IA) and a report submitted to the Human Tissue Authority (HTA) for consideration. This assessment is designed to further protect the donor by ensuring that the relationship between the donor and recipient is genuine, that the donor has the capacity to consent, that the consent given is informed and voluntary, and that no reward is attached to the donation (Human Tissue Authority, 2013). This again aims to minimise harm by identifying situations in which donors may be subject to coercion, manipulation or where they may be exploited. IAs come from a variety of professional backgrounds, such as retired healthcare staff and members of the clergy. They receive formal training and accreditation by the HTA.

It is advised that all living donor cases are formally discussed at a multi-disciplinary team meeting, where decisions related to the particular circumstances of each case can be made. These meetings should include all members of the transplant team and
provide a forum in which to address issues or concerns. The team involved in the care of the donor are separate to the team involved in the care of the recipient, which ensures that the best interests of both donor and recipient can be established independently and that no bias is introduced.

Due to a lack of evidence on psychosocial outcomes in living donors, guidelines regarding the psychological assessment of living donors are less prescribed when compared to the physical assessment. A formal evaluation of the donor’s anticipated psychological benefits is also not mandated. Consequently transplant centres within the UK and across the world vary considerably in how they assess living donors psychologically, with some conducting an informal assessment, followed by a referral to a psychologist or psychiatrist if indicated, and others performing a formal psychological assessment routinely (Duerinckx et al., 2014).

The relative psychosocial contraindications to living kidney donation are previous or current mental health illness, active substance abuse, dependence on prescribed medication, self-harming behaviour or significantly dysfunctional family relationships, particularly between recipient and donor. It is recommended that a referral for a formal mental health assessment is made in these circumstances to help establish whether proceeding with donation is safe. Again, this advice focusses on reducing the risk of harm to the donor following donation. All unspecified donors donating to a stranger undergo a mental health assessment, which although no longer legally mandatory is considered best practice. Unspecified donation is discussed further in chapter seven.

Donors withdraw and are withdrawn from the living donor workup process for a variety of reasons. The commonest medical reason is the presence of cardiovascular disease (ischaemic heart disease or heart failure) (Calder and Chang, 2004) and other reasons include incompatibility with the recipient, insufficient baseline renal function and surgical unsuitability. The same paper by Calder and Chang found that voluntary withdrawal was the commonest single reason for not donating (27%). Reasons for donor withdrawal included work commitments, a change of mind, fear of the risks and planning a pregnancy. If a potential donor wishes to withdraw but feels unable to discuss the reasons with their recipient, a letter containing a non-specific statement about the donor’s unsuitability is provided, thereby providing a reason for why they cannot donate. Although this may be perceived as deceitful, it is provided so that
donors feel free and able to withdraw at any time. In the event of a donor being withdrawn for medical reasons, the transplant centre retains a duty of care towards that individual and is responsible for ensuring that all medical diagnoses are followed up either locally or by the individual’s general practitioner. It is also recommended that psychological support should be provided to those who are disappointed by not being able to donate or those who find it difficult to reach a definitive decision.

Guidance for the preferred surgical management of living kidney donors throughout their hospital stay is also described in the BTS guidelines. Donors are required to receive prophylactic treatment for thromboembolic events, such as deep vein thrombosis and pulmonary embolism, and must be operated on either by a consultant or under direct consultant supervision. The UK guidelines recommend the use of laparoscopic surgery for living donors and where open surgery is to be performed, the use of a mini-incision technique is preferred to a standard open nephrectomy (which involves a large wound). This is supported by numerous papers in the academic literature which have compared different aspects of post-operative recovery following the use of different surgical techniques. Pure laparoscopic, hand-assisted laparoscopic and minimally invasive surgery are preferred as they all have been found to reduce analgesic requirements, shorten hospital stay and lead to a faster return to normal physical functioning (Hadianastassiou et al., 2007, Chandak et al., 2009, Wilson et al., 2011, Yuan et al., 2013). The short-form 36 questionnaire (Ware and Sherbourne, 1992) has been used extensively to compare health-related quality of life (HRQoL) outcomes between different surgical techniques. Studies have either demonstrated an improvement in HRQoL outcomes with newer techniques or no disadvantage (Jackobs et al., 2005, Rodrigue et al., 2006b, Schnitzbauer et al., 2007, Dols et al., 2009, Harryman et al., 2009, Nicholson et al., 2011, Yuan et al., 2013).

Prior to surgery, all living kidney donors are required to give written, informed consent. As part of this process, donors must be made aware of the risks and benefits of surgery, both to themselves and their recipients. In practice, again due to a lack of evidence on psychosocial outcomes in living kidney donors, attention is most commonly placed on explicitly detailing the risks of surgery to the donor and the benefits to the recipient (Parekh et al., 2008, Valapour et al., 2011, Gordon, 2012). The risk of death from living kidney donation is currently quoted as 3 in 10,000 donations (Segev, 2010). In this same paper, mortality was higher in men, in black donors and in
donors with hypertension. However, the long-term risk of death was no higher in living donors than when compared to an age and co-morbidity matched sample.

Post-operative deaths have been reported following living kidney donation in the UK, although some of these were reported up to 18 months after donation and it is not clinically plausible for them to be directly related to living donor surgery. Deaths were caused by myocardial infarction, pulmonary embolism and uterine cancer. The commonest causes of death after living kidney donation are pulmonary emboli, hepatitis and cardiac events, such as myocardial infarction and arrhythmias (Bennett and Harrison, 1974, Uehling et al., 1974, Najarian et al., 1992). These rates of death are comparable with the annual risk of dying in a road traffic accident in the USA (0.02%) (Kasiske et al., 1996, British Transplantation Society, 2011). Long-term survival after living donor nephrectomy is at least equal to age and co-morbidity matched and age, sex and ethnicity matched cohorts (Ibrahim et al., 2009, Segev, 2010).

Unlike the risk of death, there are no studies that provide a definitive estimate of the rate of morbidity after living kidney donation. In the UK, registry data with mandatory reporting has shown the major morbidity rate to be 4.5% for laparoscopic and 5.1% for open donor nephrectomy (Hadjianastassiou et al., 2007). Major morbidity was defined as “the incidence of at least one of the following complications in any one donor: need for splenectomy, reoperation, deep venous thrombosis (DVT), pulmonary embolism, pneumothorax requiring the insertion of tube thoracostomy (chest drain), pneumonia or haemorrhage necessitating blood transfusion”. The rate of any morbidity (defined as “the incidence of at least any one complication per donor”) was 10.3% for laparoscopic living donor nephrectomy and 15.7% for open surgery. Such complications included prolonged postoperative ileus, constipation, diarrhoea, urinary tract infection, urinary retention necessitating re-catheterisation, wound infection, hematoma, superficial wound dehiscence, arrhythmias, pulmonary oedema, epidural related problems and allergic reactions.

Donors are recommended to undergo early follow up once they are discharged from hospital to ensure that they are making sufficient progress after surgery and that they are being appropriately supported. A history, physical examination and blood tests are typically performed in order to detect post-operative complications, such as a wound infection. Donors are anticipated to make a full recovery by three months (British Transplantation Society, 2011). Long-term surveillance of donors is considered best
practice and is encouraged by the National Donor Registry, which is held by NHS Blood and Transplant. This provides a forum for the assessment of a donor's general health status, including an assessment of blood pressure, kidney function and urinalysis. This assessment can be conducted at the centre where the donation took place, the referring nephrology unit or by the donor's general practitioner. All UK centres are mandated to submit data before and after donation to ensure that the value of the Registry data is optimised. The follow up of international donors is especially difficult, as these donors do not always return to the UK for health checks and the availability of healthcare in their native country is variable. On-going psychosocial support is also necessary for some donors, especially in cases where the transplant has been unsuccessful or when the recipient has died. Practices vary between centres and are subject to local protocols.

In summary, the UK living kidney donation guidelines provide an excellent framework with which to physically assess and manage living kidney donors. It is clear from these guidelines that donors undergo extensive medical testing and that every effort is made to make sure that they are suitably fit to donate and that they will not suffer any long-term physical health problems as a result of living donation. The risks of surgery are well documented and are discussed on multiple occasions by different members of the transplant team. Follow up is mandatory and donors are encouraged to undergo annual health checks.

**Beneficence in Living Kidney Donation**

When returning to the principlist theory of medical ethics, the principles of autonomy and justice are, in part, satisfied. Although the principle of non-maleficence will never be entirely satisfied (as there will always be a physical harm caused by surgery with no resultant physical benefit), it is partially fulfilled by the large number of measures in place which ensure that the short and long-term physical harms are minimised as much as possible. The principle of beneficence and the psychosocial aspects of non-maleficence (i.e. the psychosocial harms) remain poorly understood. Consequently the current UK living kidney donation guidelines are lacking in evidence-based guidance on the psychosocial assessment of living kidney donors. This issue is by no means limited to the UK. A recent systematic review of thirty-four publications (Duerinckx et al., 2014) concluded that there was no consensus, nor concrete guidance, on whether every living donor required psychological screening, what psychosocial factors should be screened for, how donors should be screened and how psychosocial issues should
be managed should they arise. This lack of evidence invariably has led to huge variability in how living donors are assessed from a psychosocial perspective. This review also discussed the different reasons behind why no uniform criteria are available; the most important of which was the lack of evidence identifying the relevant psychosocial risk factors.

As well as determining who is at risk of psychosocial harm from donation it is also important to identify who is likely to benefit. In addition to satisfying the principlist approach to living donor ethics, an assessment of benefit may allow a donor who is physically sub-optimal to donate. As things stand, establishing donor beneficence is not a mandatory requirement as part of the living donation workup process and therefore it plays very little, if any role in the ‘best interests’ assessment of living donors. If it is included it is done so in an informal, subjective manner. For some individuals, the assessment of how much they may benefit from donating may be the difference between donating and not. For example, one may argue that in some circumstances it may be in a donor’s best interest to donate, despite the presence of underlying risk factors that may affect their physical health. Such an example may be an old or obese parent who is the only compatible donor to their child who will die should they not receive a transplant. This will become even more important in future years as the donor pool expands to include donors who are older, obese or those with multiple co-morbidities.

In addition, living kidney donation is playing an increasingly crucial role in the advancement of kidney transplantation, including transplantation across blood group and tissue type barriers. The success of kidney transplantation, especially in children, now means that recipients are outliving their first transplant and require subsequent transplants which are increasingly immunologically complex. This is due to the formation of antibodies which, put simply, can have implications for the immunological suitability of both deceased and living donors. The National Living Donor Kidney Sharing Scheme has facilitated a number of transplants that otherwise would not have taken place and the practice of unspecified donation has also become increasingly popular. As well as providing much needed kidneys into the donor pool, organs from unspecified donors have also been used to initiate living donor chains, through which a series of donor-recipient pairs are able to donate to one another, thereby further facilitating kidney transplants that would otherwise not be possible (Melcher et al., 2013).
It is therefore more important than ever to understand the psychosocial harms and benefits of living kidney donation. As transplantation becomes more complex and new ground is visited, the predictability of recipient outcomes is much reduced. It is now also not uncommon for both donor and recipient to be considered medically, surgically or immunologically high risk. Without a means of assessing or quantifying the psychosocial harms and benefits of donation, transplant clinicians are left to make very difficult and complicated decisions about whether a donor-recipient pair should proceed. A more in depth appreciation of the psychosocial factors affecting living kidney donation is necessary not only to ensure that living kidney donation is ethically permissible, but also that donors are optimally cared for.
Chapter 2

A Review of Psychosocial Outcomes after Living Kidney Donation

As discussed in the preceding chapter, the number of studies exploring psychosocial outcomes following living kidney donation are significantly fewer than those addressing the physical aspects of living kidney donor selection and surgery. Consequently, there are few evidence-based guidelines available to aid the assessment of living kidney donors from a psychosocial perspective. This chapter will describe and critique the available evidence on the psychosocial outcomes following living kidney donation. The literature specific to stress, personality and wound healing and unspecified kidney donation are discussed separately in chapters 6 and 7, respectively.

Commentaries, Case Series and Qualitative Studies

Qualitative research, case reports and commentaries on living kidney donation have been present in the academic literature across every era of living donation. Initially there were a number of case reports and commentaries which expressed concerns regarding the mental health of living donors, which led some experts to conclude that donors required more psychiatric attention than the recipient. This was principally due to experiences of loss (Kemph, 1967), grief and mourning (Kemph, 1970), and the fact that the donor can only benefit through self-satisfaction and psychological gain (Schumann, 1974). Rates of depression and suicide, especially in the event of graft or recipient loss, were also a concern (Higgerson and Bulechek, 1982, Weizer et al., 1990).

A systematic review and thematic synthesis of qualitative studies addressing the motivations and experiences of living kidney donors was published in 2012 (Tong et al., 2012a). This review included 26 studies involving 478 donors who donated between 1977 and 2008. Studies incorporating interviews, focus groups or observations of living kidney donors were included. All studies reported the number and characteristics of participants but only 7 described the patient selection process. Quotes were provided in 21 studies. Six themes were identified that related to the participants’ decision to become a living kidney donor, of which one related to personal benefit. The remainder were compelled altruism, inherent responsibility, accepting risks, family expectations and spiritual confirmation. The impact of donation and post-operative adjustment in donors was divided into 3 themes: renegotiating identity, renegotiating roles and renegotiating relationships. The authors describe
renegotiation as the adjustment that is made by the donor to these factors. The pertinent themes related to living donor outcomes are discussed in detail below.

Personal benefit was anticipated pre-operatively by few donors and included benefits related to the social impact of transplantation (increased participation in social activities) and the positive impact on both the recipient and the family as a whole. Improvement in quality of life for both parties was a particular anticipated benefit for spousal donors. Some expected living donation to improve the relationship that they had with the recipient. With each of the post-operative themes, adjustments made by living donors were divided into both positive and negative. These are displayed in Figure 2.1.

![Figure 2.1 - Thematic schema of living donor experiences and perspectives; renegotiating identity, roles and relationships after kidney donation (Tong et al., 2012a)](image)

Positive outcomes after living donation included a new appreciation of life and positive outlook for the future. Life was considered more valuable and some adopted a healthier and more productive lifestyle as a result. Donation was commonly described as a unique, gratifying and meaningful experience that had resulted in having a profound effect on the donor’s self-perception and identity. Donation increased self-worth, confidence and made donors more compassionate. Some were attributed 'hero
status’, were praised or given attention, or received recognition from their community. Some donors felt that relationships within their family and with their recipient strengthened after donation. Some were also adamant that repayment or gratitude was not expected and that they did not want their recipients to feel beholden. These donors actively discouraged discussion about their donation and expressed a desire to ‘move on’ with life.

Negative outcomes included feelings of fear and vulnerability, and heightened concerns about developing kidney failure and needing dialysis or a transplant. Donors also expressed concerns about other aspects of their physical health including susceptibility to illnesses, fertility and sexual function. Some donors expressed a sense of loss or dehumanisation after donation, whilst others felt depressed, anxious and distressed. The time period over which these emotions were experienced varied from being within the peri-operative period to several months. Negative emotions and the duration of time that these emotions were felt were associated with recipient outcomes, the donors’ post-operative recovery and their ability to return to normal activities. Recipient death or graft loss left donors feeling “devastated” and “mentally paralysed”, with some experiencing feelings of guilt, despair and inadequacy; that their kidney had not been “good enough”.

Some family donors experienced a difficult recovery after surgery due to the multiple roles they had adopted throughout the recovery period, including “patient, donor, carer, family provider and homemaker”. This was challenging, stressful and hindered recovery. Financial difficulties, due to the inability to work, were also experienced. Feelings of hurt, neglect, jealousy and rivalry were experienced amongst sibling donors, who felt resentful that their recipient had received the most attention. Many donors became protective, worried and concerned about their recipient and were preoccupied with the possibility that the kidney may fail. This was especially the case if the donor and recipient were very close and where the wellbeing of the donor was heavily dependent on the recipient’s health and wellbeing. Donors’ expectations of their recipients were very high, with ambitious hopes of them leading a better quality of life that was healthier and more fulfilling. If the recipient was perceived as having an unhealthy lifestyle this led to feelings of frustration and anger. A few donors acknowledged that they became controlling towards the recipient in this situation, in an attempt to regulate their lifestyle choices.
Since the review by Tong et al was published there have been a handful of additional qualitative studies and case reports that have addressed different issues related to the living kidney donation process, including decision making, donor expectations, stressors and the opinions of transplant professionals (Alnaes, 2012, De Groot et al, 2012a, Gill, 2012, McGrath et al., 2012, Yeh et al., 2012, Tong et al., 2013). The findings are in keeping with the themes discussed above and they add further insight into the complexities of living donation. They additionally identify a requirement for increased psychological support around the time of donation (Gill, 2012), a need for more sophisticated quantitative studies and the need for a greater understanding of both the psychosocial harms and benefits associated with donation, in order to properly advise donors during the informed consent process (Tong et al., 2013). Despite identifying a need for more sophisticated quantitative studies, no qualitative study has attempted to provide specific guidance on how such a study should be conducted and what factors should be measured. In addition, no study has aimed to identify which pre-operative psychosocial factors may influence post-operative physical or psychosocial recovery.

**Quantitative literature**

In recognition of the ethical and moral issues unique to living kidney donation a systematic review was published in December 2006 in the American Journal of Transplantation (Clemens et al., 2006). The review aimed to “quantify donor psychosocial health after nephrectomy” by reviewing all English language psychosocial questionnaire studies, both prospective and retrospective, that contained more than ten participants. Specifically, the authors looked at the impact of living kidney donation on social function, self-concept, body-image, psychological wellbeing and quality of life. A description of the studies is provided in Table 2.1.

A number of methodological issues were identified in the appraisal of the studies. There was a scarcity of prospective evidence (just 10 studies) and a significant proportion (14; 27%) had minimal to no demographic information, nor relevant descriptive information, provided. Time to donor follow up was not always reported and where it was, it varied from months to many years after donation. Seven retrospective studies recruited donors who had donated over a period of 20 years or more (Toronyi et al., 1998, Fehrman-Ekholm et al., 2000, Isotani et al., 2002, Chen et al., 2004, Jordan et al., 2004, Fisher et al., 2005, Dahm et al., 2006). The results of these studies inevitably included donors who had donated very recently (months) alongside those who had donated many years ago.
Table 2.1: Description of studies included in the review by Clemens et al (2006)

<table>
<thead>
<tr>
<th>Description</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number of studies</td>
<td>51</td>
</tr>
<tr>
<td>Total number of living kidney donors</td>
<td>5139</td>
</tr>
<tr>
<td>Timeframe of studies</td>
<td>1969 to July 2006 (37 years)</td>
</tr>
<tr>
<td>Countries from which data has been published</td>
<td></td>
</tr>
<tr>
<td>United States of America (USA)</td>
<td>43%</td>
</tr>
<tr>
<td>Germany</td>
<td>10%</td>
</tr>
<tr>
<td>Canada</td>
<td>6%</td>
</tr>
<tr>
<td>Number of UK studies</td>
<td>1 (Lumsdaine et al., 2005)</td>
</tr>
<tr>
<td>Prospective studies</td>
<td>10</td>
</tr>
<tr>
<td>Retrospective studies</td>
<td>41</td>
</tr>
<tr>
<td>Average follow up time</td>
<td>4 years (1 week to 37 years)</td>
</tr>
<tr>
<td>Psychosocial data collected alongside physical health outcomes</td>
<td>46</td>
</tr>
<tr>
<td>Number of studies that included donors whose recipients had suffered graft loss or had died</td>
<td>26</td>
</tr>
<tr>
<td>Studies with a control group</td>
<td>29</td>
</tr>
</tbody>
</table>

Response rates were not always calculable, but where stated averaged 71% and ranged between 33% and 95%. Information on non-responders was collected in just 11 studies and only 5 compared the characteristics of responders and non-responders.

The use of routine pre-operative psychological or psychiatric screening was described in 23 studies, the majority of which were from the USA (11 studies). Very few reported the presence of a mental health history prior to donation (Bennett and Harrison, 1974, Morris et al., 1987, Smith et al., 2004). Twenty-nine studies compared living kidney donors to non-donor controls, which included the general population, medical outpatients, potential living kidney donors, healthy individuals and family members of the recipient. Demographics or relevant descriptors for control groups were provided for only 4 studies and few were matched for age, gender or other factors, such as level of education (Gouge et al., 1990, Westlie et al., 1993, Schover et al., 1997, Tanriverdi et al., 2004).

A broad range of validated and non-validated questionnaires were used across the 51 studies. The commonest validated questionnaire was the short-form 36 health survey.
(SF-36) (18 studies), the short-form 12 health survey (SF-12) (3 studies) and the Beck Depression Inventory (BDI) (3 studies). A single questionnaire was used in 38 studies. Investigator developed questionnaires were used in 35 studies, only a small sample of which were validated (Smith et al., 1986, Gouge et al., 1990, Westlie et al., 1993, Rudow et al., 2005, Stothers et al., 2005), tested for reliability (Simmons and Anderson, 1982, Westlie et al., 1993, Corley et al., 2000, Fisher et al., 2005, Stothers et al., 2005) or piloted (Smith et al., 1986, Stothers et al., 2005). The methods of questionnaire completion were not always described, but where done so, questionnaires were usually self-administered by post, the internet or in the outpatient clinic.

When considering future research into the psychosocial aspects of living kidney donation, the review authors stressed the importance of conducting large, multicentre, prospective, cohort studies which used appropriate controls and followed participants regularly for a prolonged period. In addition, it was suggested that key characteristics of eligible and participating donors should be reported, along with response rates, recruitment methods and information on non-responders, and that strategies should be adopted to help minimise the drop-out rate of those donors who experienced inferior outcomes.

Since 2006, 35 quantitative studies have been published and these are summarised in Table 2.2. Collectively, they appear to have followed some of the recommendations made by Clemens and colleagues. With the exception of one study, all included at least one validated measure. There were a higher proportion of prospective studies (42.9% at present vs. 19.6% in 2006), studies using more than one measure (31.2% at present vs. 24.5% in 2006) and studies using a control group (60.0% at present vs. 56.9% in 2006). A number of issues relating to the reporting of key characteristics persisted, including some studies which did not report the timeframe of the recruitment period, donor demographics, follow up time or questionnaire response rates. Where response rates were reported, they again varied considerably (36-97%).

The way questionnaire answers were given was also unclear at times, i.e. whether they were self-completed or obtained within the context of a clinic appointment by a transplant professional. The proportion of studies using a health-related quality of life (HRQoL) outcome measure also increased (68.6% at present vs. 43.1% in 2006) and consequently, HRQoL was the most commonly measured psychosocial factor (26 studies). The majority of studies used the SF-36 (24 studies - 92.3%) either in isolation
Table 2.2: Summary of quantitative studies published since July 2006

<table>
<thead>
<tr>
<th>Reference</th>
<th>Journal</th>
<th>Country</th>
<th>Prospective Study</th>
<th>No. of Donors</th>
<th>Mean Donor age (Range)</th>
<th>Length of follow up (Range)</th>
<th>Response rate</th>
<th>Control / comparison group</th>
<th>Measures used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lima et al (2006)</td>
<td>NDT Brazil</td>
<td>No</td>
<td>(&gt;2 years prior to study)</td>
<td>100</td>
<td>43 (---)</td>
<td>8 yrs (---)</td>
<td>94%</td>
<td>Healthy people (age and gender matched)</td>
<td>SF36</td>
</tr>
<tr>
<td>Virzi et al (2007)</td>
<td>Transplant P Italy</td>
<td>Yes (Pre vs. 4m)</td>
<td>(2002-2004)</td>
<td>48</td>
<td>54 (33 to 81)</td>
<td>N/A</td>
<td>---</td>
<td>No</td>
<td>SF36; Clinical interview; Structured interview for Renal transplantation; Mini-Mental State examination; Hamilton rating scale for depression; Hamilton anxiety scale; Self-rating anxiety scale</td>
</tr>
<tr>
<td>Feltrin et al (2008)</td>
<td>Transplant Int Italy</td>
<td>No</td>
<td>(2002-2004)</td>
<td>59</td>
<td>--</td>
<td>16.2 months (5-30)</td>
<td>86%</td>
<td>General population survey</td>
<td>SF36; TxQu</td>
</tr>
<tr>
<td>Minnee et al (2008)</td>
<td>Transplantation The Netherlands</td>
<td>Yes (Pre vs. 1,2,4, 12, 26 and 52 weeks)</td>
<td>(2002-2006)</td>
<td>105</td>
<td>--</td>
<td>N/A</td>
<td>---</td>
<td>No</td>
<td>SF36; MFI (fatigue); VAS (pain)</td>
</tr>
<tr>
<td>Shrestha et al (2008)</td>
<td>Transplant P United Kingdom</td>
<td>Yes (Pre vs. Post – Different donors)</td>
<td>(---)</td>
<td>66</td>
<td>44 (---)</td>
<td>4.6 years (3m – 28 years)</td>
<td>85%</td>
<td>Potential donors who did not proceed</td>
<td>SF36</td>
</tr>
<tr>
<td>Tellioglu et al (2008)</td>
<td>Transplant P Turkey</td>
<td>No</td>
<td>(12-126m)</td>
<td>50</td>
<td>55.8 (29-70)</td>
<td>5.5 months (12-168)</td>
<td>---</td>
<td>General population</td>
<td>SF36</td>
</tr>
<tr>
<td>Nejatiafsa et al (2008)</td>
<td>Transplantation Iran*</td>
<td>No</td>
<td>(---)</td>
<td>424</td>
<td>28 (---)</td>
<td>---</td>
<td>---</td>
<td>No</td>
<td>Paykel Life Events Scale (stress); WHOQOL-BREF</td>
</tr>
<tr>
<td>Slakey et al (2008)</td>
<td>Dialysis Transplant USA</td>
<td>No</td>
<td>(---)</td>
<td>81</td>
<td>39 (---)</td>
<td>5 (---)</td>
<td>52%</td>
<td>No</td>
<td>Self-designed questionnaire</td>
</tr>
<tr>
<td>Padrao and Sens (2009)</td>
<td>Clin Transplant Brazil</td>
<td>No</td>
<td>(---)</td>
<td>69</td>
<td>44 (25-64)</td>
<td>---</td>
<td>73%</td>
<td>Non-donor healthy volunteers</td>
<td>SF36; WHOQOL-bref</td>
</tr>
<tr>
<td>Reference</td>
<td>Journal</td>
<td>Country</td>
<td>Prospective Study (Time points)</td>
<td>No. of Donors (Timeframe of recruitment)</td>
<td>Mean Donor age in years (Range)</td>
<td>Length of follow up (Range)</td>
<td>Response rate</td>
<td>Control / comparison group</td>
<td>Measures used</td>
</tr>
<tr>
<td>-------------------------</td>
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<td>---------------------------------</td>
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<td>--------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Wiedebusch et al. (2009)</td>
<td>Transplant P</td>
<td>Germany</td>
<td>No</td>
<td>161 (1985-1995)</td>
<td>56 (32-80)</td>
<td>61.3 months (2-280)</td>
<td>81%</td>
<td>No</td>
<td>SF36, HADS, Freiburg Questionnaire of Coping with Illness (FQCI)</td>
</tr>
<tr>
<td>Taskintuna et al. (2009)</td>
<td>Int J Psychiat Clin</td>
<td>Turkey</td>
<td>No</td>
<td>42 (---)</td>
<td>42 (25-58)</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>Haemodialysis patients, transplant recipients and healthy volunteers</td>
</tr>
<tr>
<td>Albertsmeier et al. (2010)</td>
<td>Transplant P</td>
<td>Germany</td>
<td>No</td>
<td>69 (1993-2003)</td>
<td>---</td>
<td>5 (---)</td>
<td>65%</td>
<td>German population scores</td>
<td>SF36</td>
</tr>
<tr>
<td>Hoda et al. (2010)</td>
<td>Transplant P</td>
<td>Germany</td>
<td>No</td>
<td>44 (2003-2008)</td>
<td>44 (32-61)</td>
<td>21 months (5-40)</td>
<td>92%</td>
<td>German population scores</td>
<td>SF36 (modified), WHOQOL-brief (modified)</td>
</tr>
<tr>
<td>Zhao et al. (2010)</td>
<td>Clin Transplant</td>
<td>China</td>
<td>No</td>
<td>84 (2002-2007)</td>
<td>45 (24-56)</td>
<td>---</td>
<td>---</td>
<td>General Chinese population</td>
<td>SF36, Social support rating scale for Chinese, BDI, Self-rating Anxiety Scale, Self-designed Qu (tested for face validity)</td>
</tr>
<tr>
<td>Chien et al. (2010)</td>
<td>Transplant P</td>
<td>Taiwan</td>
<td>Yes (Pre vs. 3m)</td>
<td>14 (---)</td>
<td>45 (28-62)</td>
<td>N/A</td>
<td>74%</td>
<td>General US population</td>
<td>SF36</td>
</tr>
<tr>
<td>Chkhotua et al. (2011)</td>
<td>Transplant P</td>
<td>Georgia</td>
<td>No</td>
<td>57 (---)</td>
<td>49 (---)</td>
<td>32m (4-57)</td>
<td>93%</td>
<td>Renal Cell Cancer patients and healthy volunteers</td>
<td>SF36, Gissen subjective complaints list, Zersen's mood scale</td>
</tr>
<tr>
<td>Clemens et al. (2011)</td>
<td>AJT</td>
<td>International (Multicentre)</td>
<td>No</td>
<td>203 (2004-2008)</td>
<td>44 (---)</td>
<td>---</td>
<td>86</td>
<td>Individuals who had undergone donor workup but failed to donate</td>
<td>SF36, 15 D (Health-related Quality of Life), Feeling thermometer, Self-designed questions</td>
</tr>
<tr>
<td>Mjøen et al. (2011)</td>
<td>AJT</td>
<td>Norway</td>
<td>No</td>
<td>1508 (1963-2007)</td>
<td>46 (---)</td>
<td>---</td>
<td>76%</td>
<td>Population sample</td>
<td>SF36, Self-designed questions</td>
</tr>
<tr>
<td>Reference</td>
<td>Journal</td>
<td>Country</td>
<td>Prospective Study (Time points)</td>
<td>No. of Donors (Timeframe of recruitment)</td>
<td>Mean Donor age (Range)</td>
<td>Length of follow up (Range)</td>
<td>Response rate</td>
<td>Control / comparison group</td>
<td>Measures used</td>
</tr>
<tr>
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</tr>
<tr>
<td>Frade et al. (2011)</td>
<td>Transplant P</td>
<td>Portugal</td>
<td>No</td>
<td>45 (2002-2008)</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>Recipients</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Self-designed socio-demographic questions</td>
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<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Donation perception questionnaire (incl. open ended qu. for qualitative analysis)</td>
</tr>
<tr>
<td>Lopes et al. (2011)</td>
<td>Transplant P</td>
<td>Portugal</td>
<td>Yes (Pre vs. &gt;1yr)</td>
<td>45 (2002-2008)</td>
<td>41 (---)</td>
<td>N/A</td>
<td>--</td>
<td>Recipients</td>
<td>Zung self-rating anxiety scale</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Zung self-rating depression scale</td>
</tr>
<tr>
<td>Vemuru Reddy et al. (2011)</td>
<td>Indian J Urol</td>
<td>India</td>
<td>Yes (Pre vs. 6m)</td>
<td>100 (---)</td>
<td>43 (---)</td>
<td>N/A</td>
<td>94%</td>
<td>No</td>
<td>WHOQOL-bref</td>
</tr>
<tr>
<td>Wiesenthal et al. (2011)</td>
<td>BJU</td>
<td>Canada</td>
<td>Yes (Pre vs. 4, 8, 12 and 16w)</td>
<td>95 (2004-2008)</td>
<td>43 (---)</td>
<td>N/A</td>
<td>88% (total sample)</td>
<td>Nephrectomy patients (benign disease and cancer)</td>
<td></td>
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<td></td>
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<td></td>
<td></td>
<td></td>
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<td></td>
<td>Post-operative recovery scale (PRS)</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Visual analogue scale (pain)</td>
</tr>
<tr>
<td>de Groot et al. (2012)</td>
<td>Transplant Int</td>
<td>The Netherlands</td>
<td>No</td>
<td>316 (---)</td>
<td>52 (25-77)</td>
<td>5 years (0.9-13.5yrs)</td>
<td>74%</td>
<td>No</td>
<td>SF36</td>
</tr>
<tr>
<td>Kroencke et al. (2012)</td>
<td>Clin Transplant</td>
<td>Germany</td>
<td>Yes (Pre vs. 3m vs. 12m)</td>
<td>79 (2005-2009)</td>
<td>53 (---)</td>
<td>N/A</td>
<td>93%</td>
<td>Healthy volunteers</td>
<td>SF36</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>HADS</td>
</tr>
<tr>
<td>Fournier et al. (2012)</td>
<td>Transplant Int</td>
<td>France</td>
<td>No</td>
<td>204 (1953-2008)</td>
<td>41 (---)</td>
<td>16.8 (---)</td>
<td>65%</td>
<td>No</td>
<td>Medico-psychosocial questionnaire (self-designed; not validated) (8 questions)</td>
</tr>
<tr>
<td>Kadioglu et al. (2012)</td>
<td>Transplant P</td>
<td>Turkey</td>
<td>No</td>
<td>30 (Feb-Aug 2011)</td>
<td>47 (---)</td>
<td>(3-12m)</td>
<td>--</td>
<td>Recipients</td>
<td>Dyadic adjustment scale</td>
</tr>
<tr>
<td></td>
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<td></td>
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<td>HADS</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>BDI</td>
</tr>
<tr>
<td>Lennerling and Forsberg (2012)</td>
<td>J Renal Care</td>
<td>Sweden</td>
<td>Yes (pre vs. 3-4w and 6-8w)</td>
<td>112 (2005-2008)</td>
<td>50 (23-70)</td>
<td>N/A</td>
<td>97%</td>
<td>No</td>
<td>Dartmouth COOP Functional Health Assessment Chart (modified)</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Additional measure of muscular strength</td>
</tr>
<tr>
<td>Reference Journal Country</td>
<td>Prospective Study (Time points)</td>
<td>No. of Donors (Timeframe of recruitment)</td>
<td>Mean Donor age (Range)</td>
<td>Length of follow up (Range)</td>
<td>Response rate</td>
<td>Control / comparison group</td>
<td>Measures used</td>
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<tr>
<td>Bahler and Sundaram (2013)</td>
<td>Yes (Pre vs. 1, 4 and ≥7m)</td>
<td>101 (---)</td>
<td>38 (19-62)</td>
<td>N/A</td>
<td>---</td>
<td>Nephrectomy patients (benign disease and cancer)</td>
<td>▪ SF36</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Klopf et al. (2013)</td>
<td>Yes (Pre vs. 1, 3, 6 and 12m)</td>
<td>501 (2001-2010)</td>
<td>---</td>
<td>N/A</td>
<td>---</td>
<td>No</td>
<td>▪ SF36</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lopes et al. (2013)</td>
<td>Yes (Pre vs. &gt;1yr)</td>
<td>45 (2002-2008)</td>
<td>41 (20-60)</td>
<td>N/A</td>
<td>---</td>
<td>No</td>
<td>▪ SF36 ▪ Zung self-rating anxiety and depression scales</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Watson et al. (2013)</td>
<td>No</td>
<td>1030 (---)</td>
<td>44 (---)</td>
<td>---</td>
<td>46%</td>
<td>No</td>
<td>▪ SF36</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Garcia et al. (2013)</td>
<td>Yes (Pre vs. 3m vs. 12m)</td>
<td>50 (---)</td>
<td>41 (25-68)</td>
<td>N/A</td>
<td>---</td>
<td>No</td>
<td>▪ SF36 ▪ Donor questionnaire</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Glotzer et al. (2013)</td>
<td>No</td>
<td>83 (2000-2010)</td>
<td>43 (---)</td>
<td>---</td>
<td>36%</td>
<td>Individuals excluded from LKD for a variety of reasons</td>
<td>▪ SF12 ▪ Addendum questionnaire (AQ)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Joshi et al. (2013)</td>
<td>Yes (---)</td>
<td>30 (---)</td>
<td>---</td>
<td>N/A</td>
<td>(- -)</td>
<td>No</td>
<td>▪ KDQol SF 1.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rodrigue et al. (2013)</td>
<td>Yes (Pre vs. 1, 6, 12 and 24m)</td>
<td>133 (2002-2010)</td>
<td>43.1 (---)</td>
<td>N/A</td>
<td>86%</td>
<td>No</td>
<td>▪ Living donor expectancies questionnaire (LDEQ)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* This study was conducted into Living Unrelated Donors, who in Iran are predominantly motivated by the financial compensation offered by the government (Malakoutian et al., 2007). Results in such studies need to be interpreted with caution.
(8 studies – 33.3%) or alongside other questionnaires. Self-designed questionnaires were used in 8 studies, of which 6 were not validated (Feltrin et al., 2008, Slakey et al., 2008, Fournier et al., 2012, Garcia et al., 2013, Glotzer et al., 2013, Joshi et al., 2013). The remaining two were tested for face validity (Zhao et al., 2010) or pilot tested by “a group of experts in living donor issues” (Clemens et al., 2011). The available quantitative literature on psychosocial outcomes after living kidney donation will now be summarised.

**Social issues**

Social issues were addressed in 33 studies and focused predominantly on the quality of relationships between donors and others, including recipients, spouses, non-recipient children and other family members. The majority of these studies included high proportions of donors who felt their relationships had either stayed the same or improved after donation (86–100%). However, only 4 studies captured this data prospectively and were therefore able to make pre- and post-donation comparisons (Simmons and Anderson, 1982, Lumsdaine et al., 2005, Minz et al., 2005, Garcia et al., 2013). These studies demonstrated no change or an improvement in social functioning and social support post-operatively. Where investigated, familial relationships were also better for the majority of donors (Feltrin et al., 2008), however this was only measured retrospectively. One study reported that donors felt their families were more loving and supportive after donation, and that they were treated with greater respect (Joshi et al., 2013). Societal relationships and levels of community involvement were also found to be unchanged or improved after donation (Gouge et al., 1990, Westlie et al., 1993, Terasaki et al., 1997, Johnson et al., 1999, Vlaovic et al., 1999, Minz et al., 2005). Social support was formally measured on one occasion as part of a retrospective study and was found to be the same as the general population (Zhao et al., 2010).

More negative findings included divorcees citing donation as a reason for, or being instrumental in, their marriage breaking down (Smith et al., 1986, Schover et al., 1997). The study by Smith et al (1986) has provided the most in-depth assessment of the impact of donation on marriage. In this study of 536 donors donating to blood-relatives alone, 371 donors had been married at the time of donation. Twenty-seven went on to separate or get divorced after donation had taken place (7.3%), 12 within the first year. A third of these donors stated that donation had been a contributing factor to their relationship breakdown. Divorce or separation was more likely in those who had felt under pressure from their family to donate and those who felt that
donation had been a substantial financial burden. Donation had also been a cause of family conflict in 10% of cases (Reimer et al., 2006). Difficulties in familial relationships correlated with post-operative health related problems in the donor (Tellioglu et al., 2008). In spousal donor-recipient pairs, post-operative levels of depression correlated positively between both parties and in donors, marital issues after donation correlated positively with levels of depression (Kadioglu et al., 2012). The financial burden of donation was assessed and was found to a large burden in 61.9% of cases (Zhao et al., 2010).

**Self-Concept and Body Image**

Self-concept was measured in 22 studies, of which 6 reported an increase in self-esteem or self-worth after donating. Self-esteem was measured prospectively in 3 studies (Simmons and Anderson, 1982, Virzi et al., 2007, Garcia et al., 2013), only 1 of which used a validated measure (the Rosenberg scale) (Simmons and Anderson, 1982). This study demonstrated that at 5-8 years after donation, self-esteem increased in 51% of donors, stayed the same in 21% and decreased in 28%. Where the self-esteem of donors was compared to the general population or non-donor controls, donors scored the same or better (Simmons and Anderson, 1982, Gouge et al., 1990, Westlie et al., 1993). Factors associated with an increase in self-esteem have not been identified.

Other positive findings included increased confidence (Bennett and Harrison, 1974), increased self-satisfaction (Karrfelt et al., 1998, Westlie et al., 1993), feeling proud, brave or heroic and a better person (Simmons and Anderson, 1982, Corley et al., 2000). Donors also described developing a better understanding of others (Eisendrath et al., 1969, Bennett and Harrison, 1974), a deeper religious faith and a sense of accomplishment (Eisendrath et al., 1969). One study reported donors feeling the same about themselves after donation (Toronyi et al., 1998) and two demonstrated that some felt they had given something up for nothing in return (Simmons and Anderson, 1982, Corley et al., 2000) (6% and 24% respectively).

Donors’ perceptions of their physical appearance have been measured in 10 studies and adverse outcomes were noted in a minority, all of which were conducted when open nephrectomy via a large flank incision was the standard surgical procedure. Some donors perceived themselves as less attractive to their partner (Smith et al., 1986) or felt that the appearance of their scar had negatively affected their self-esteem (Schostak et al., 2003). Body image was not addressed in any of the studies conducted
since 2006, which may be due to the introduction of laparoscopic surgery and its associated smaller scars.

**Psychological wellbeing**

Psychological wellbeing was measured in a 36 studies. Of those reporting positive findings, large proportions of donors felt happy (Corley et al., 2000) or happier since their donation took place (Duque et al., 1999, Fisher et al., 2005, Jackobs et al., 2005). Donors also felt that they were treated as "special" by others (Schover et al., 1997, Fisher et al., 2005). Where pre-operative psychological expectations were considered, the majority of donors felt that at least some of their expectations had been met (Jackobs et al., 2005). Donors were demonstrated to have both similar and superior outcomes when compared to the general population and potential donors (Westlie et al., 1993, Prandini et al., 1987, Gouge et al., 1990, Varma et al., 1992, Yoo et al., 1996).

Less positive outcomes included feeling ignored and disappointed with the emotional experience of donation (Schover et al., 1997, Fisher et al., 2005), unappreciated (Brown and Sussman, 1982) and abandoned (Smith et al., 1986). Donors also reported experiencing disappointment, sadness and loss (Fisher et al., 2005, Dahm et al., 2006). Adverse recipient outcomes (graft loss or death) were associated with feelings of guilt, waste, futility and worthlessness (Brown and Sussman, 1982, Schover et al., 1997).

**Depression**

Depression was measured in 12 studies. The majority of donors (75 to 95%) experienced no symptoms of depression after donation (Prandini et al., 1987, Schover et al., 1997, Johnson et al., 1999, Fisher et al., 2005, Minz et al., 2005, Virzi et al., 2007, Wiedebusch et al., 2009, Taskintuna et al., 2009, Zhao et al., 2010, Chkhotua et al., 2011, Lopes et al., 2011, Kroencke et al., 2012). The broad difference in rates of depression is likely to be a reflection of the wide-ranging post-operative timeframe over which depression was measured (3 months to 31 years) and the different depression scales used (Hamilton rating scale for Depression, Hospital Anxiety and Depression Scale, Beck’s Depression Inventory, Zerssen’s mode scale and the Zung self-rating depression scale). Four studies reported rates of post-operative depression in donors when in fact they had not measured depression at all. These studies used one of the short-form measures (SF-12, 20 or 36) or a non-validated, self-designed questionnaire; neither of which are validated measures of depression. The results from these studies must therefore be read with caution as they demonstrate a misinterpretation of the findings from the questionnaire. Additional negative findings include reports of donors feeling
depressed, low, downhearted or tearful (Fisher et al., 2005, Simmons and Anderson, 1982), however these were relatively infrequent.

Of the 4 studies that measured depression prospectively, two reported no difference between pre- and post-operative scores (Virzi et al., 2007, Kroencke et al., 2012) and two reported a significant worsening of mood post-operatively (Minz et al., 2005, Lopes et al., 2011). The study by Minz and colleagues (2005), which used the Beck’s Depression Inventory (BDI), demonstrated that depression scores were significantly worse 3 months after donation. Despite including 75 donors in total, the significant increase in depression scores were attributed to just 4 donors, all of whom developed mild depression after donation. It is unclear from the results and analysis presented in the paper where these conclusions were drawn from and again, the results must therefore be interpreted with caution.

Factors associated with increased rates of depression included negative recipient outcomes (Kroencke et al., 2012) and being single (Wiedebusch et al., 2009). The impact of negative recipient outcomes on depression is supported by a large American study of 4650 donors which reviewed database links between the Organ Procurement and Transplantation Network (OPTN) and a private health insurer. This study assessed the number of health insurance claims for depression made by donors and compared them to the general public (Lentine et al., 2012). No significant difference in the rates of depression in donors was demonstrated, however recipient death and graft loss predicted an increased risk of depression in unrelated donors. There was no association in related donors. Low mood has also been demonstrated to be negatively correlated with health-related quality of life (Wiedebusch et al., 2009).

On occasions where donors have been compared against control groups, the outcomes have been different depending on which control group has been used. Where healthy volunteers, non-donors (those within the family who could have volunteered to donate but who chose not to), those undergoing a nephrectomy for kidney cancer, transplant recipients and haemodialysis patients have been used (Chkhotua et al., 2011, Taskintuna and Ozcurumez, 2011), donors have been found to have significantly lower rates of depression. Where age and gender matched controls have been used (Tanriverdi et al., 2004, Yoo et al., 1996) no significant difference in rates of depression has been demonstrated.
Anxiety

Anxiety was measured in 12 studies using both non-validated and validated questionnaires. When measured retrospectively, high proportions of donors displayed no anxiety after donation (86 to 94%) (Bennett and Harrison, 1974, Smith et al., 1986) but, as discussed above within the context of depression, it is difficult to ascertain a true rate of anxiety due to the different measures used and the wide-ranging post-operative timeframe over which it was measured (months to many years). One study reported an increase in pre-existing depression and anxiety in two donors (5%), however this was measured retrospectively and did not use a validated measure (Prandini et al., 1987). Donors were merely asked whether they felt they were more depressed or anxious after donation.

Where anxiety was measured prospectively, the results were contradictory. Prospective studies demonstrated an improvement in rates of anxiety (Minz et al., 2005), no difference in rates of anxiety (Virzi et al., 2007) and an increase in anxiety towards death (Yoo et al., 1996) when comparing pre and post-operative scores. Results were similarly contradictory when donors were compared with controls. Donors were found to have both higher (Zhao et al., 2010), lower (Taskintuna and Ozcurumez, 2011) and comparative levels of anxiety (Tanriverdi et al., 2004) when compared to different control groups. No associated factors or predictors of anxiety have been identified.

Stress

Stress related to the living donation process was referred to in a number of studies, although no objective validated measures of psychological stress have ever been used. Specific causes included donor surgery, complications and recovery (Smith et al., 1986, Schover et al., 1997, Johnson et al., 1999, Fehrman-Ekholm et al., 2000, Tanriverdi et al., 2004, Fisher et al., 2005, Minz et al., 2005). Donors were also concerned about both short and long-term health implications following donation (Simmons and Anderson, 1982, Johnson et al., 1999, Corley et al., 2000), and more specifically, the health implications of living with a single kidney and the possibility of developing kidney failure themselves (Gouge et al., 1990, Schover et al., 1997, Tanriverdi et al., 2004, Fisher et al., 2005, Rudow et al., 2005, Minz et al., 2005, Neuhaus et al., 2005, Stothers et al., 2005, Dahm et al., 2006).

Financial matters were also a cause of stress, predominantly for donors donating in the USA or Canada, and included loss of earnings, the prospect of financial hardship, and
difficulty in obtaining health insurance. Financial stresses were also an issue in an Iranian study which included individuals who received payment for donation (Nejatisafa et al., 2008). Unsurprisingly this study reported high numbers of donors who had experienced at least 1 stressful life event in the 6 months before donation (95%), of which the majority of issues were financial. Donors were also concerned about recipient outcomes, the prospect of the transplant failing and the side effects of immunosuppression treatments (Brown and Sussman, 1982, Tanriverdi et al., 2004, Giessing et al, 2004).

Other psychiatric symptoms
When measured, large proportions of donors experienced no psychiatric or psychosomatic symptoms and demonstrated lower psychiatric scores than non-donors, both before and after donation (Karrfelt et al., 1998, Reimer et al., 2006, De Graaf Olson and Bogetti-Dumlao, 2001). Psychiatric symptoms were associated with a history of substance abuse (Morris et al., 1987) and negative recipient outcomes (Brown and Sussman, 1982). There were no reported suicides in the quantitative literature, however in one study (Schover et al., 1997) as many as 11% of donors whose recipients had either died or lost their graft had experienced suicidal ideation. Where psychiatric symptoms were measured prospectively, post-operative scores were found to be significantly higher after surgery. These included sensitivity, paranoia, aggression, intractability, obsession and somatization (Varma et al., 1992, Taghavi et al., 2001). One study compared mental health visits and psychotropic medication use between donors and non-donor controls (Clemens et al., 2011) and reported no significant difference.

Health-Related Quality of Life (HRQoL)
Health-related quality of life (HRQoL) was the most extensively investigated psychosocial factor and was measured in 55 studies. Most of these studies were retrospective (38 studies) and used one of the short-form health surveys (i.e. SF-12, SF-20, SF-36). The majority reported that living kidney donors had an equivalent or improved quality of life on all or some subscales of the SF-36 when compared with range of controls, which included the general population, healthy individuals, non-donor controls (those who volunteered to donate but did not proceed) and those undergoing nephrectomy for benign disease or cancer. Laparoscopic surgery was associated with equivalent or improved quality of life as measured by the SF-12 and the SF-36.
Retrospective studies that included control groups demonstrated that decreased HRQoL in donors was associated with poor post-operative donor outcomes and recipient graft loss (Tellioglu et al., 2008, Feltrin et al., 2008, Padrão and Sens, 2009), less time since donation and higher concurrent depression, anxiety and fatigue scores (Wiedebusch et al., 2009, de Groot et al., 2012). HRQoL was also reduced in those with lower societal engagement or participation within their community, and in donors who had higher expectations (de Groot et al., 2012). HRQoL was lower in Iranian donors when compared to controls as the majority of these donors donate due to financial hardship (Nejatisafa et al., 2008).

Higher HRQoL was associated with improvements in familial relationships (Feltrin et al., 2008). A retrospective study which assessed post-operative HRQoL annually on the anniversary of donation demonstrated that recipient death was associated with a significant decrease in quality of life in the year immediately after death (Watson et al., 2013), however this then improved in subsequent years. For those donors whose recipients’ grafts were failing, quality of life was also lower and became lower still after the graft had failed. This was most pronounced where the graft was lost less than 6 months after transplantation. The authors suggest that these findings may be a reflection of a grieving process (for the loss of the kidney) that did not reach closure. It may also be a reflection of guilt or carer burden if the donor is responsible for the care of the recipient.

Eighteen prospective HRQoL studies were conducted, some with and some without a control group. Studies differed on whether a change in post-operative quality of life was demonstrated, and this is again likely to be due to the varied time points at which quality of life was measured (weeks to years). Only one study demonstrated no significant difference in pre- and post-operative scores and that was when quality of life was measured at 12 months (Lopes et al., 2013). Another study demonstrated an increase in mental health scores post-operatively (Joshi et al., 2013), however the time since donation took place was not recorded. The majority of prospective studies demonstrated a drop in HRQoL after donation. This was for total scores, the physical component score and subscales and the mental component score and subscales (Shrestha et al., 2008, Virzi et al., 2007, Chien et al., 2010, Kroencke et al., 2012, Bahler and Sundaram, 2013, Smith et al., 2004, Bergman et al., 2005, Lumsdaine et al., 2005). Only one study demonstrated no change in mental health component scores across all time frames (Kroencke et al., 2012). On occasions where quality of life was measured at more than one time point, physical component scores, which initially decreased after
donation, returned to normal at both 4 month (Kroencke et al., 2012) and 12 month time points (Bahler and Sundaram, 2013, Garcia et al., 2013).

One study compared HRQoL in donors to both healthy individuals and the general population (Kroencke et al., 2012) and demonstrated that pre-operatively, donor scores were on par with healthy controls and were higher than the general population. Post-operative donor scores decreased and were significantly worse than healthy controls, yet not statistically different to the general population. This brings into question the suitability of a control group which includes members of the general public rather than healthy controls. A general public sample will include a proportion of individuals who are affected by illness, whereas living donors are normally healthier because they have been extensively tested and selected because they are free from illness. By demonstrating that post-operative donors have the same HRQoL as the general public, one may be falsely reassured that no change in HRQoL has taken place after surgery when in fact this finding demonstrates a decrease in HRQoL. Factors affecting quality of life included concurrent anxiety and depression, recipient complications, female gender, previous psychiatric history and previous social issues (Kroencke et al., 2012, Bahler and Sundaram, 2013, Lopes et al., 2013, Vemuru Reddy et al., 2011).

**Psychosocial Issues Related to Physical Recovery**

Psychosocial issues related to physical recovery was a concept not included in the Clemens review but has been investigated in more recent years. Psychosocial issues include chronic pain and the rate of return to a normal level of functioning. Rates of chronic moderate or severe pain in the scar were quoted in two studies (10% and 15%, respectively (Hoda et al., 2010, Lima et al., 2006) and when older and younger donors were compared, less pain was demonstrated in older donors (Minnee et al., 2008). Return to normal levels of function was assessed in 3 studies (Slakey et al., 2008, Wiesenthal et al., 2011, Lennerling and Forsberg, 2012) and rates varied considerably within donor groups. Interestingly, when donors were compared to those undergoing a nephrectomy for either cancer or benign disease, donors took longer to recover and took more time off work, which is counterintuitive given that they were fitter, younger, lighter and more active before surgery (Wiesenthal et al., 2011). These findings could be due to a number of unidentified reasons, but suggest that donors are either affected more psychosocially than other nephrectomy patients or that there are other factors that may be impeding their recovery, such as the need to look after their recipient who is also recovering from surgery at the same time.
Regret

Regret was another concept not addressed in the Clemens review, despite being explored in the majority of the studies included in it (32 studies). After 2006, regret has been assessed in 11 studies (Lima et al., 2006, Shrestha et al., 2008, Tellioglu et al., 2008, Slakey et al., 2008, Hoda et al., 2010, Zhao et al., 2010, Mjoen et al., 2011, Frade et al., 2011, Vemuru Reddy et al., 2011, Fournier et al., 2012, Garcia et al., 2013). Rates of regret varied from between 0-17%, however was as high as 40% in a study that used an open nephrectomy technique (Wolf et al., 2001). Risk factors for regret included graft loss, complications after surgery, being an unrelated donor and a follow up time of less than 12 years (Mjoen et al., 2011). Contradicting this is a second study which demonstrated no regret in individuals whose recipient had died or where the graft had been lost (Vemuru Reddy et al., 2011). Across all of these studies, regret was measured in a variety of different ways, including asking donors outright whether they regretted their decision, asking whether they would donate again or asking whether they would recommend living donation to others.

Donor Benefit

Only one quantitative study has focussed on living donor benefit (Rodrigue et al., 2013). This American multicentre study utilised the Living Donor Expectancies Questionnaire (LDEQ), a validated measure developed by the same group (Rodrigue et al., 2008), with a view to identifying trajectories of perceived benefit over the first 2 years after donation. This study, involving 133 donors, focussed on measuring pre-operative expectations before assessing the degree to which those expectations were met at 1, 6, 12 and 24 months post-operatively. Personal growth, and interpersonal and spiritual benefit were chosen as these were identified from the literature as being the most commonly reported benefits.

Five distinct trajectory groups were identified: 1) those with moderate expectations that were met, 2) those with low-expectations that were exceeded, 3) those with moderate expectations that were exceeded early before returning to baseline, 4) those with high expectations that were never met and that continued to fall and 5) those with moderate expectations that were not met initially but then returned to baseline. Overall, the majority of donors fell into groups 1 to 3, indicating that pre-donation personal growth (71%), interpersonal benefit (90%), and spiritual benefit (79%) expectancies initially were met or exceeded following donation, although trajectories differed after the 1-month assessment.
This study suggests that for the majority of donors a benefit is perceived following donation and that the pattern of benefit varies considerably based on both donor characteristics and recipient outcomes. Personal growth and interpersonal benefit expectations were less likely to be met in those aged 35-49 and women were more likely to report a declining personal growth and an increasing personal benefit. Older and non-white donors were more likely to exceed their spiritual growth expectations. Donors whose recipients died, suffered graft loss, or where their health status did not appear to improve were understandably more likely to have a persistent decline in expectations or a retraction in perceived benefit after an early increase. Although this study is unique in its approach to living donor benefit, and is helpful in both proving the presence of benefit and in identifying who is likely to have their expectations met, it provides no concurrent objective psychosocial data, which would have been helpful in assessing the psychosocial impact of both met and unmet expectations.

Summary and critique of the available literature

It is evident from the quantitative and qualitative literature discussed above that attempts have been made to understand the psychosocial aspects of living kidney donation. The systematic review by Clemens et al (2006) and thematic synthesis of qualitative studies performed by Tong et al (2012) identified a number of themes related to post-operative donor adjustment. It is clear that although a number of donors undergo positive adjustment after surgery, a number also undergo a negative adjustment process which includes symptoms of depression, anxiety and stress, to name but a few.

The systematic review by Clemens et al (2006) identified a number of issues related to quantitative living donor research and since that review was published, some progress has been made to improve the methods used. Some attempt has also been made to identify which factors may be associated with both positive and negative outcomes, as well as describing what those outcomes may be. The large numbers of quantitative studies demonstrate that high proportions of donors experience no decline in their relationship with their recipient (86-100%), no depression (75-95%) and no anxiety (86-94%). Donors report feeling proud, heroic and brave and the majority do not regret their decision to donate (83-100%). There does not appear to be a higher incidence of psychiatric problems within the donor population, however donor suicides have been reported in the qualitative literature (Weizer et al., 1990). HRQoL is by far the most measured concept and has broadly varied results. Negative psychosocial outcomes are more commonly reported in prospective studies (i.e.
reduced HRQoL and increased depression and anxiety after donation) and include feelings of abandonment, being ignored and disappointment. Poor outcomes in the recipient are associated with increased rates of depression and lower HRQoL. Stress has never been formally measured in living kidney donors, however donors have reported feeling stressed about all aspects of the surgical procedure and recovery, recipient outcomes, money and both the short and long-term implications on their own health.

Although the outcomes discussed above are predominantly positive, they must be interpreted with some caution due to the poor quality of some of the studies. This is something which is also acknowledged by the authors of the systematic review. These issues include the paucity of pertinent information in some studies, such as the method of recruitment, eligibility criteria and reasons for loss of follow up. Sample sizes were frequently small with variable response rates, which may have resulted in spurious and inaccurate conclusions or type 2 statistical errors. The circumstances of non-responders are also incredibly important, however these are infrequently reported. The experience of non-responders is especially important in the event of adverse events, as these have been shown to be associated with inferior psychosocial outcomes. In addition, there may also be a proportion of donors who were unable to respond due to medical, surgical or psychological problems that had occurred after their donation had taken place.

Due to the high proportion of retrospective studies within the living donor literature one must also consider the influence of recall bias, especially when questionnaire data was collected over 20 years after the donation had taken place. Prospective studies were more likely to report negative outcomes, however these assessments were commonly made on one occasion shortly after surgery and it is unclear how long these effects lasted for (Reimer et al., 2006). The suitability of different control groups used for comparison must also be questioned. Living kidney donors are healthy individuals who are selected on that very basis and it is therefore difficult to find a suitable control group. Comparing living donors to national data from population surveys may underestimate the psychosocial morbidity attributable to living donation. This is principally because the questionnaire scores are likely to be lower in a population survey due to the inclusion of individuals who are affected by both acute and chronic illness (Kroencke et al., 2012). By claiming that living donors are on par with this group post-operatively, when they are likely to have been significantly better pre-operatively, may artificially reassure the reader that living donation has no negative
effects. Clemens and colleagues suggest the use of potential donors who are medically and psychologically fit, but who do not donate for other reasons. Although this group may be a more closely matched control in terms of baseline characteristics and physical health, one must not underestimate the potential psychosocial implications of not being able to donate, especially if these individuals were the only potential donor for their recipient (Allen et al., 2014).

One must also consider the methodologies used within the quantitative literature, the suitability of the questionnaire tools selected and the way that the results were interpreted. Many studies used investigator-developed questionnaires, only a few of which had been externally validated or pilot tested. Questionnaires were completed in different settings and in different ways. Where donors were asked questions directly by, or in the presence of, a member of the transplant team, it is possible that they would have demonstrated high social desirability by responding positively, regardless of their experiences (Yoo et al., 1996, Schover et al., 1997).

The reliance on the SF-36 and similar generic health-related quality of life (HRQoL) outcome measures is also a concern. These questionnaires became popular within the living donor literature following their use in studies comparing different techniques for living donor nephrectomy. HRQoL questionnaires have been used extensively to compare laparoscopic surgery with open surgery and their results have been published alongside other clinical data, such as length of stay and complication rates. It is wholly appropriate to use these measures within this context as the aim of these studies was to identify whether there was a difference in HRQoL between two surgical techniques. However, HRQoL tools have subsequently been adopted into the psychosocial outcome literature, typically as either one-off measurements of HRQoL or as a comparison between donors and other groups.

One may hypothesize that the increase in popularity of HRQoL measures may have been because they were well validated, standardised measures that were easy to administer, available in different languages and widely published elsewhere in the living donor literature. However, whilst generic standardised measures allow for comparisons to be made between different populations, they are unlikely to be sufficiently sensitive to assess the complexities inherent to the living donor population and therefore they should not be used in isolation (Dew et al., 2012, Fournier et al., 2012, Tong et al., 2012a). This is supported by evidence within the literature which has demonstrated positive HRQoL scores alongside concurrent negative findings in
other psychosocial domains, such as depression and anxiety (Mjoen et al., 2011, Frade et al., 2008, Virzi et al., 2007, Wiedebusch et al., 2009, Kok et al., 2006, Perry et al., 2003, Rodrigue et al., 2006a, Dols et al., 2009).

Some studies have also reached false conclusions from HRQoL data; for example, concluding that donors experienced no symptoms of depression based on a HRQoL score alone (Prandini et al., 1987, Schover et al., 1997, Johnson et al., 1999, Fisher et al., 2005). Although the SF-36 is a well validated tool that provides a straightforward means of assessing both the physical and psychosocial aspects of HRQoL, it is not a validated to screen for or diagnose depression. Such conclusions are inaccurate and provide false assurance of living donor outcomes.

One also gets the impression that the results of the HRQoL studies may have been somewhat misinterpreted by the transplant community. These studies measure health-related quality of life, however the ‘health-related’ aspect is commonly omitted from the manuscripts. The implications of this are that the reader may falsely assume that the measure provides an overall assessment of life quality. Demonstrating an equivalent or improved HRQoL score is likely to mislead the reader that all other aspects of the donor’s life are also either the same or improved after donation. In addition, given that donors are likely to be above average in terms of their health status prior to donation, because they have successfully passed a series of complex medical tests, it is no surprise that their health-related quality of life scores are above average pre-operatively. It is also no surprise that these scores drop post-operatively and then, in the majority, return to baseline as the individual recovers from major surgery. It therefore seems counterintuitive to draw definitive quality of life conclusions from an assessment tool that is specific to health, especially when also appreciating that living donation is a psychosocially complex topic. This large body of HRQoL literature is commonly referred to by transplant professionals when discussing the psychosocial aspects of living kidney donation and, given that it does not provide conclusive evidence in support of living kidney donation, the appropriateness of this is questionable.

Despite the large number of studies into the psychosocial aspects of living kidney donation, there is a lot that remains unknown about living kidney donors. There is no clear understanding of what one should consider a bad psychosocial outcome and whether it is simply a worse post-operative score than at baseline. There is also a limited understanding of what factors are associated with worse outcomes across a
range of psychosocial concepts. Socially, there is little information on who is at higher risk of relationship breakdown, marital or financial issues and poor social support. In terms of psychological wellbeing, again little is known about how and why certain individuals experience feelings of disappointment or abandonment. Depression, stress and anxiety are all emotions that are commonly referred to within the context of living donation, however it is unclear whether living donation causes these emotions or whether these are present concomitantly and result in poor outcomes after living donation takes place. There is also very little data on what impact psychosocial factors have on physical recovery and whether suboptimal physical outcomes can be predicted based on pre-operative psychosocial questionnaire scores.

One of the main issues that prevent definitive conclusions being drawn from the available literature appears to be a substantial difference in how the living kidney donation has been approached and therefore what conclusions can be drawn from the results. The qualitative literature has consistently provided evidence in support of living donation being a psychosocially complex topic, which is multifaceted and difficult to fully understand. In contrast, the quantitative literature is full of very simple studies, the majority of which only measure one psychosocial factor in a small sample. This lack of congruence means that there are no quantitative studies that are even close to providing an extensive assessment of living kidney donors. This issue has been brought to the surface in recent years, with many studies concluding that not only is more research needed, but also that the available quantitative evidence is inadequate and potentially falsely reassuring.

The different control groups used throughout the literature are also an issue. This has not only has led to donors being compared to a broad range of different individuals, which therefore makes it difficult to compare studies with one another, but also there is no consensus on what the best control group would be. A logical solution to these issues may be to use donors as their own control and compare pre-operative scores with one or more post-operative scores across a range of different psychosocial questionnaires. This would also allow an assessment of the trajectory of different psychosocial factors after donation; something which cannot be determined from the existing literature due to the variability in post-operative time points at which psychosocial questionnaires have been completed.

It is perhaps somewhat surprising that the practice of living donation has progressed to the point that it is at without a more in-depth assessment of living donors having
taken place. In the early days of transplantation the “best interests” argument was less in favour of living donation because donor surgery was associated with significant harm to the donor (i.e. an open operation with a long recovery time) and questionable outcomes in the recipient. There was consequently more concern and more discussion about whether living donation could be justified. As transplantation has evolved and advanced, the benefits to the recipient have increased and include longevity of life as well as an improved quality of life. The introduction of laparoscopic surgery has also meant that the risks to the donor have decreased. This has resulted in the best interests argument being more in favour of living donation and the bar has therefore been set at minimising physical harm to the donor rather than proving a benefit. In addition, one may consider the benefits to the donor to be obvious; i.e. the obvious benefit to the recipient is likely to have an obvious positive effect on the donor. As has been demonstrated from the studies discussed above, this is clearly not always the case. To date, only one study has focussed on donor benefit (Rodrigue et al., 2013) and the need for more benefit-focused research is becoming more apparent in order to help the donor and their transplant team make a true risk-benefit assessment (Allen et al., 2014). There is also an established literature on benefit finding within health psychology, where individuals derive benefits from traumatic events, such as a diagnosis of cancer (Tomich and Helgeson, 2004, Helgeson et al., 2006) and it would be interesting to explore whether this also plays a role within living donation.

What is also apparent from the literature is that the concerns related to living donation expressed in the early days of transplantation were not wholly addressed and have been largely overlooked until more recent years. The significance of donor psychosocial health has now resurfaced, possibly because living donation is now very common or perhaps because the importance of psychosocial health and wellbeing on physical recovery is now more established. Additionally there are an increasing number of complicated transplants taking place. To some degree these transplants carry with them the same level of uncertainty as was demonstrated in the early days of transplantation, where the risks of death and graft loss were high. It is plausible that as these transplants become more frequent and donors and recipients are willing to accept higher risks, transplant professionals must reconsider the psychosocial implications to the donor in the event that things do not go according to plan.

Chapter Summary
This chapter has identified that although the available literature suggests that the majority of donors have a very positive experience of living kidney donation, there are
a number of issues in the way this research has been conducted that makes the accuracy of these findings questionable. Advancement within this field can only come from conducting a more comprehensive quantitative study that seeks to address a number of the issues identified in the current literature. It is important for this study to be prospective and longitudinal, making an assessment of donors before and after donation and at more than one post-operative time point. It is important that questionnaire data is collected on a number of different psychosocial factors through the use of well validated measurement scales and that donor-specific data is captured in order to determine whether there are any factors that may be associated with benefit or harm after donation.

A longitudinal study was conducted as part of this thesis and is outlined in chapters 4 and 5. A control group was not used as I was unable to identify a group of surgical patients whom I thought were appropriate to compare with living kidney donors. Donors were instead used as their own controls and comparisons were made between pre-operative and post-operative questionnaire scores.

Prior to conducting the longitudinal study it was necessary to perform a qualitative study that explored the field of living kidney donation in more depth. Although the format of the quantitative study had already been decided, a qualitative study was deemed important for two reasons. Firstly, it was imperative to develop a broader understanding of the issues affecting living kidney donors in the UK so that I could identify which psychosocial factors to measure as part of the quantitative study. Secondly, it was important to establish which donor-specific factors may be associated with either a positive or negative psychosocial outcome. As well as generating hypotheses for the quantitative study, the results of the qualitative study also guided the selection of validated questionnaires and determined which new questions needed to be written. The details of the qualitative study are outlined in the following chapter.
Chapter 3
Identifying Predictors of Psychosocial Outcome in Living Kidney Donors

Qualitative Research in Healthcare

‘Qualitative research’ is a an overarching term that encompasses a wide range of approaches and methodologies located within different research disciplines (Ritchie and Lewis, 2003). The aim is to achieve a breadth and depth of understanding for a particular research question and is more suited to exploring complex issues. Words instead of numbers are used (Creswell, 2009), which result in large volumes of rich detailed data being produced per participant. This allows the researcher to build a “complex, holistic picture” (Creswell, 1998) of the topic and participants in question by extracting the themes, concepts and explanations from the data. Participant samples are therefore traditionally much smaller than a quantitative study and participants are systematically and purposively selected based on key criteria as defined by the researcher rather than through random sampling (Mays and Pope, 1995). In order to facilitate the collection of such rich data the researcher should ideally be in close contact with the participant; be that by immersing themselves in the participants’ environment or developing an environment in which personal, intimate information can be shared. The significance of a particular viewpoint or statement is not attributed to the number of participants who share a similar view; rather each person’s opinion is equally valid independently of others.

Although qualitative research methods have a long history in the social sciences, research in medicine and surgery has more conventionally been conducted via hypothesis driven clinical trials or experiments in which traditional quantitative approaches are taken (Meadows, 2003, Pope and Mays, 1995). As discussed in chapter 2, the majority of research studies into living donation have been carried out through quantitative methods. This approach is more likely to have been preferred as those interested in living donation (i.e. doctors and nurses) are more familiar with quantitative research methodologies. The increase in popularity of qualitative and mixed methods healthcare research is a reflection of the attitudinal shift within modern healthcare, where patient perspectives offer a significant contribution to the planning and development of research, investigations and treatments. The importance of psychological and social factors on recovery from illness and surgery are also now very much a part of the holistic, multi-disciplinary approach to patient care. This necessitates research that provides a broader, more comprehensive understanding of
relevant factors affecting an individual, their decision making process and health-related behaviour. These factors are not easily measured quantitatively and require a more in-depth, qualitative approach. This method of approach is particularly useful in areas that have received less attention or when attempting to conduct a quantitative study into a more complex area, such as quality of life (Pope and Mays, 1995). The identification of factors predictive of psychosocial outcome after living kidney donation fits both of these criteria for a qualitative approach.

**Justification of a qualitative study**

A review of the literature in chapter two concluded that there was insufficient data on psychosocial outcomes in living kidney donors. Qualitative studies exploring outcomes in living kidney donors suggest that living donation is psychosocially complex, with a potentially “profound and multifaceted impact” on the donor's life (Tong et al., 2012a). The quantitative studies performed to date do not reflect this and instead have adopted a more simplistic approach, commonly using different validated questionnaires to measure either one or a small selection of psychological factors, including stress, anxiety or depression (Clemens et al., 2006). “Quality of life” has commonly been measured using the Short-Form measures and these are too generic to capture the more complex issues specific to living donors. The majority of previous studies conclude that living donation is safe, however they lack explanations over why some donors benefit from donation and why others experience more negative outcomes such as depression or anxiety. In addition, different demographic data collected across these previous studies offer no clear indication of impact on positive or negative outcomes.

A qualitative study was deemed a necessary prerequisite to conducting a more comprehensive, quantitative study into living kidney donation. This is because it would provide detailed data, from which hypotheses could be generated. These hypotheses would then guide the selection of validated measures for use within the quantitative study and guide the writing of new questions where previous validated measures did not exist. The qualitative study had two principal aims:

1. To identify the key psychosocial issues affecting living kidney donors
2. To determine what factors may impact psychosocial outcomes in living kidney donors
Methods

Qualitative Study Design

The qualitative research design process as described by Ritchie and Lewis (Ritchie and Lewis, 2003) was adopted for this study. A cross-sectional approach was selected over longitudinal case studies due to limitations on time (a longitudinal case-based approach would have required a minimum of three interviews over a minimum of 12 months, followed by a lengthy period for analysis). A cross-sectional study was designed to involve a larger sample of different participants at a variety of stages of donation, ranging from the initial discussion with a living donor co-ordinator to many years post-donation. Specific issues related to living donation did not exist in the natural environment so the generation of new data was necessary.

Donors who were yet to donate and those who had already donated were recruited. In-depth interviews were chosen as the most appropriate data collection method. This was because the use of open-ended questions would allow for a deep exploration of the donor's feelings and perspectives on their experience of living donation. It would also invite discussion of topics and issues most important or of most interest to the donor and therefore would be more likely to identify new concepts. In addition to the use of open-ended questions, the study was in keeping with the other key characteristics of in-depth interviewing (Guion et al., 2001). These included the use of audio recording software to record donors' responses and the use of active listening skills to reflect upon what the donor was saying and then seeking clarification and understanding throughout the interview. The interviews were conducted with the aid of a topic guide, which allowed key questions to be planned in advance. This encouraged the interview to become conversational, with questions flowing from previous responses where appropriate. An environment in which a personal one-to-one discussion could be held was preferred to a group setting. This approach was selected as it was more conducive for disclosure and discussion of sensitive information and would allow participants to speak openly.

Interview data was analysed using framework analysis; a form of thematic analysis (Ritchie and Spencer, 1994). Framework analysis was selected because its systematic and comprehensive approach is especially useful when a specific research question is in mind (Pope et al., 2000).
Materials

Topic Guide
Two topic guides, one each for pre- and post-operative donors, were designed (Appendix 1 and 2, respectively). The different stages of the donation process provided broad headings under which topics and open-ended questions were listed. The headings were as follows:

1. Pathway to donation
2. Decision making and the risks of surgery
3. The donation process
4. Expectations
5. Conclusions

Topics were ordered chronologically to assist with information recall and participants were guided through the events in a logical, systematic manner. Both topic guides commenced with an open question asking how the participant's donor status was established. This covered the recipient's illness and the impact on the donor, the recipient and their loved ones. Participants were probed to recall their decision making process to become a donor and their consideration of the risks of surgery. The opinions of individuals within their social network were also discussed with particular attention to those who were against the donation. For the post-operative donors, additional questions about their experience of surgery and convalescence were also included.

Expectations of donation and surgery were approached differently depending on whether the participant was a pre- or post-operative donor. For the pre-operative donors questions focussed on how the participant thought life would change after the donation and what they hoped the outcome would be. For the post-operative donors questions were rephrased to assess what expectations were held pre-operatively, whether any had been met thus far and which remained outstanding. Regret was discussed with all participants and both groups were asked whether they anticipated having any regrets in the future and what specific factors may make them feel regretful. In addition the post-operative group were asked whether they had felt any regret since their donation took place. The interview was closed by inviting each participant to talk about anything that had not been covered as part of the interview topic guide.
**Validation of Topic Guide**

Prior to commencing the interviews the topic guide was reviewed by a patient and public involvement group, a cross-section of transplant professionals (including doctors and senior nurses) and qualitative researchers from King's College London. The details are described below.

The patient and public involvement group was attended by three post-operative living kidney donors at different stages of their recovery (3 weeks, 3 months and 1 year). The interview methodology, topic guide, location of interviews, reimbursement of expenses and the necessity of audio recording was discussed. Subsequent management of the interview transcripts and the data analysis were also briefly discussed. Each donor was given a copy of the topic guide and a stamped addressed envelope to take away and return with comments if necessary. No additional comments were made.

The six doctors consulted were from transplant surgery (3), nephrology (2), and psychiatry (1). The nursing staff included all five living donor co-ordinators, the living donor matron, the outpatient transplant sister and a consultant living donor nurse. Each was given the topic guide and an opportunity to discuss any issues that they thought were not covered. No new topics were identified.

Two qualitative researchers from King's College London were consulted on the study design and topic guide. Each thought the design was appropriate given the time allocated and the purpose for which it was being conducted. The sampling strategy was also discussed. It was agreed that the most important factors for participant selection would be the relationship between the donor and their recipient and (for the post-operative group), the amount of time that had elapsed since the donation took place. This was to ensure that post-operative donors who had donated over a broad time frame were included, in order to establish whether their feelings towards living donation had changed over time.

Following each of these sessions minor adjustments were made to the topic guide and circulated to the research team for review.

**Participant Selection**

A purposive sample of English speaking living kidney donors was selected based primarily on the relationship between the donor and their recipient and secondarily, for the post-operative donors, on the length of time after donation. With regard to
donor-recipient relationship, the aim was to reflect the proportions of each group that donate at Guy's Hospital each year. The majority of donors are first degree relatives (parent to child, child to parent or siblings) followed by spouses and then other distant relatives and friends. The sample of post-operative donors was larger in order to include post-operative donors who had donated over a broad time frame.

*Method of Recruitment*

*Pre-operative participants*

Pre-operative participants were identified from the living donor patient lists managed by the living donor matron. Patients were either contacted by telephone and sent a patient information leaflet or recruited via the patient education session held in the Guy's Hospital Renal Clinic two weeks before their scheduled surgery. The patient information leaflet explained the purpose of the study and that the information disclosed as part of the interview would not be discussed with the clinical team and would not influence any future care they received. Details regarding anonymisation, storage and disposal of data were also outlined. Participants were invited back to Guy's Hospital at a mutually convenient time, fitting in with other clinical visits where possible. No interviews were conducted on the day of recruitment.

*Post-operative participants*

Post-operative participants were identified from living donor follow up clinics conducted each fortnight in the renal outpatient department at Guy’s Hospital. Attendance lists were screened beforehand to determine the relationship between the donor and recipient. Medical notes were screened to identify anyone with a less favourable post-operative outcome. As with the pre-operative group, participants were given a patient information leaflet and invited back to Guy's Hospital at a mutually convenient time. For those post-operative participants who were recent donors, (those who had donated less than 4 weeks previously), identification was made via the living donor patient lists as for the pre-operative sample. Donors making additional visits to the hospital for the purposes of research were offered full reimbursement of their travel expenses.

*Procedure*

*Consent*

On the day of interview all participants were reminded of the pertinent points noted in the information sheet. Written informed consent was obtained in person for all
participants immediately prior to the interview taking place. A copy of the consent form was given to each participant for their records.

Location of Interviews
To reduce the potential impact of the Hawthorne effect (Landsberger, 1958) interviews were conducted away from the clinical environment, so that the research interview was less like a medical consultation. Interviews took place in private, in individual consulting rooms within the Clinical Research Facility on the 15th floor of Guy’s Hospital, London. This allowed for guaranteed room availability in an area which was quiet and away from the main clinical areas where interruptions are common.

Interview style
The topic guide was designed to facilitate the use of open questions by listing themes for discussion rather than specific questions where possible. All interviews were conducted by the same researcher (NHM). A course on in-depth interviewing, run by the National Centre for Social Research, was attended by the researcher which provided feedback on the researcher’s interview style. No significant problems were identified. Eye contact, the use of verbal and non-verbal encouragers (which are ways of prompting participants to continue talking) and body language were all used to facilitate the interview by helping the participant feel at ease and subsequently build rapport. Additional measures to reduce the Hawthorne effect included the interviewer wearing more casual clothes than would be expected from a member of clinical staff and the interviewer playing no part in the clinical care of the participants.

Recording Equipment
The interviews were recorded with an Olympus WS-750M Digital Voice Recorder. The equipment was checked prior to each interview to identify optimum placement for voice detection and to avoid problems that may lead to loss of data, such as equipment failure or loss of power supply.

Aftercare
After the interview a letter was sent to each participant’s General Practitioner (GP) informing them of the participant’s involvement in the study. No details regarding

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1 The Hawthorne effect (also known as the observer effect) is the impact of the researcher on the research subject, potentially inadvertently changing their behaviour. This response, independent to experimental manipulation, is a response to the fact that participants know they are being studied.
what had been disclosed as part of the interview were included. Participants provided written consent for their GP to be contacted. A copy of the patient information leaflet was enclosed with the GP letter. A copy of the GP letter, consent form and patient information leaflet was also placed in the participant’s medical notes and an entry made on the hospital Electronic Patient Record. Participants were reminded of the research team’s contact details should they require any additional support following the interview. Any participants whose psychological state was of concern were discussed with the principal investigator and a consultant psychiatrist was contacted for advice. This was required on one occasion and no intervention was deemed necessary. One participant requested a copy of their transcript this was sent at the earliest opportunity.

**Data analysis**

Interview data was analysed using framework analysis; a method of thematic analysis developed and described by Ritchie and Spencer (Ritchie and Spencer, 1994). Framework analysis has become an established and rigorous method of analysing qualitative data (Furber, 2010), which in its rawest form is unorganised and plentiful. Framework analysis was selected because it is dynamic, systematic, methodical and comprehensive. It facilitates easy return to the original text which assists in transparency and allows others to formulate judgements from the data (Srivastava and Thompson, 2009). It is also useful when a specific research question is in mind and when time is limited as it is more structured than other types of qualitative research (Pope et al., 2000).

**Stages of Framework Analysis**

Framework analysis has five distinguishable stages: 1) Familiarisation; 2) Identifying a thematic framework; 3) Indexing; 4) Charting and 5) Mapping and interpretation (Ritchie and Spencer, 1994). Each stage will be discussed in turn, outlining what must take place and how this was undertaken in this study.

**Familiarisation**

Familiarisation requires the researcher to become immersed in the collected data in order to become better acquainted with it. Activities include listening to interviews, reading and re-reading transcripts and revisiting observational notes made at the time of interaction with the participants. This allows the researcher to develop an overview of the main ideas in the data (Furber, 2010) and note down themes and trends. It is also important to revisit the study aims to ensure that the data can be applied (Ritchie
et al., 2003). For this study, six transcripts (three pre-operative, three post-operative) were selected for review as part of the familiarisation stage. The transcripts were selected based on donor-recipient relationship and their diversity in experiences. Each transcript was read and re-read by two researchers and ideas, themes and trends were noted in the margins.

**Identifying a thematic framework**

This stage involves revisiting the notes made in the familiarisation stage in order to devise a framework for further analysis. The key concepts and themes through which the data is most easily categorised are identified and form the basis of the preliminary stages of data organisation. These concepts and themes become headings for categorical codes, which are subsequently used in the indexing stage. Assigning numerical codes to individual themes and categories provides a way of sectioning the data so that further analysis can subsequently take place. Main headings are typically allocated a number, under which subthemes can be classified. Intellectually the process involves making judgements about the meaning and relevance of issues contained within the data in order to start organising it in a manner which is conducive to formal analysis. The framework for this study was identified by the same two researchers undertaking the familiarisation stage. The headings used in the topic guide were used to form a basic structure for the analysis, which was subsequently modified and refined to best fit the data. Subheadings were added, and some removed, prior to finalisation of the framework.

**Indexing**

Indexing (also known as ‘coding’) is the process through which the framework is applied to the data. Each individual transcript is revisited and small sections are allocated one or more numerical classification codes, depending on which subthemes are applicable. This requires the researcher to make judgements on each individual statement and ascertain which part of the framework it is most relevant to. This process is commonly time consuming, especially when transcripts are indexed by hand. In this study, original transcripts were indexed by hand on printed copies. This process was performed by two researchers for the first six transcripts to increase validity. It was not possible for every transcript to be double coded. Once each transcript was coded, a computerised approach of cutting and pasting coded sections of text was used to collate quotes underneath individual subthemes. Sections remained identifiable by noting the participant and line numbers from each transcript. Important quotes were retained in their original form for use in the writing up stage.
Charting

Charting is a means of displaying the data in a way that makes it easy to analyse. Each main theme is allocated a chart (or grid) which contains cells for the text. Each subtheme is allocated to a column and each participant is allocated to a row. Data is then removed from its original context and summarised prior to being inserted into the appropriate chart cell. This process allows for both thematic or 'between-case' analysis (by reading down a column) and case study or 'within-case' analysis by reading across a row (Srivastava and Thompson, 2009). For this study the charts were devised on Microsoft publisher to allow for printing on A3 paper. The row-order of participants remained the same throughout the individual charts to allow for easy comparisons to be made.

Mapping and interpretation

This is the point at which final data analysis takes place. Although the process of data analysis is on-going from the beginning, this final stage is the point at which the original aims and objectives are re-examined and the answers to research questions sought. Thematic analysis of the data involves revisiting each subtheme column and comparing and contrasting individuals' views and experiences. This is done in order to establish associations and explanations that may assist the answering of research questions. For this study, the columns of each subtheme were read individually and notes made on the recurring themes, trends and experiences. This data was then reorganised diagrammatically on plain pieces of A3 paper. Displaying the data visually assisted in linking different themes and concepts together and helped establish relationships between different factors. This process was undertaken independently by two researchers who then met to discuss what they had both extracted from the data. The final theoretical framework was subsequently agreed.

Credibility and rigor in qualitative research

Qualitative research is commonly criticised for lacking scientific rigour, generalizability and reproducibility when compared to quantitative research (Mays and Pope, 1995, Meadows, 2003). This is principally because of the variety of methods that may be used to ensure the reliability and validity of individual findings. The statistical approaches used in quantitative research are inappropriate for qualitative work as different methods for sampling and analysis are used. The concepts behind the principles of validity, reliability and objectivity of data are much the same in both qualitative and quantitative research but are assessed in different ways (Miles and
Credibility

Credibility denotes that the conclusions reached make sense, are credible to the people that are studied and the findings are generally consistent. The conclusions from this study were discussed with the remainder of the research team and the study was presented to members of the clinical team who were able to relate to and understand the findings. Overlapping between participants was experienced within some of the themes, which indicated that the findings were rich in internal consistency. The findings were also very specific to the living donor cohort when compared to other patient groups.

Transferability

Transferability describes the application of the data beyond the study group and the context in which the study took place. Although living donors are a relatively finite group when compared to the general population, our findings were generalisable to donors being cared for in other centres across the country and the world. Our data contained participants of different ages, genders and relationships to their recipients. A broad range of experiences came through from the data and although individual cases brought new and interesting perspectives, the findings were likely to be broadly applicable.

Dependability

Dependability requires consistency and stability over time and across researchers (Meadows, 2003) and necessitates revisiting the research questions on multiple occasions to ensure the data meets the requirements of the questions. Examples of consistency and stability in this study include the data collection stage (where each interview was conducted in the same way, by the same individual and in the same setting) and the analysis stage (where the same researchers were used). The research questions were also constantly referred to as part of the interview and analysis process to ensure the questions were being addressed.

Confirmability

Confirmability relies on transparency (in the way the study and analysis was conducted) and on the data being obtained and analysed without bias. Examples of transparency in this study include the interviews being transcribed by someone
independent from the research team, by double coding where possible and by using verbatim quotes throughout the discussion of findings. The study was also sufficiently transparent to allow an independent researcher to participate in the mapping and interpretation stage. The charts contained participant labels, quotes and line numbers for ease of cross-reference to the original transcripts so that summaries and findings could be confirmed.

**The Researcher’s Perspective**

Similar to the Hawthorne effect (Pope and Mays, 1995) the researcher themselves can bring their own personal experiences into the research process (Elliott et al., 1999). The principal researcher in this study was a surgical trainee with six months clinical experience in transplantation and living donation, predominantly taking care of donors on the ward pre- and post-operatively. The researcher had no experience in assessing whether potential donors would be suitable for transplantation and therefore had a limited appreciation of the nuances of individual cases. This allowed the researcher to approach the research topic with an open mind whilst also using clinical knowledge where appropriate. Further reflection is provided at the end of the chapter [see “Reflexive Practice”].

**Results**

**Participants**

Twenty-four living kidney donors were invited to participate in the study. All agreed to participate, however one donor was unable to attend for an interview due to a scheduled trip abroad. The participation rate was therefore 95.8%. Twenty-two attended for an interview at Guy’s Hospital and one interview was conducted by telephone. Demographic details are listed in Table 3.1. For parents and siblings, each birth order category (donating to eldest, middle or youngest child or sibling) was represented. Three donors were involved in the National Living Donor Kidney Sharing Scheme. The interviews took place over a six week period in February and March 2012.
<table>
<thead>
<tr>
<th>Study ID number</th>
<th>Gender</th>
<th>Age at interview</th>
<th>Donating / Donated to...</th>
<th>Time pre- or post-op</th>
<th>Lived with Recipient</th>
<th>Primary caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>PREOP01</td>
<td>M</td>
<td>32</td>
<td>Brother a</td>
<td>- 7 days</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>PREOP02</td>
<td>M</td>
<td>57</td>
<td>Son</td>
<td>-8 days</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>PREOP03</td>
<td>F</td>
<td>54</td>
<td>Son</td>
<td>-1 day</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>PREOP04</td>
<td>M</td>
<td>31</td>
<td>Fiancé</td>
<td>n/a*</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>PREOP05</td>
<td>M</td>
<td>25</td>
<td>Friend</td>
<td>-24 days</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>PREOP06</td>
<td>M</td>
<td>29</td>
<td>Son</td>
<td>-1 day</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>PREOP07</td>
<td>M</td>
<td>34</td>
<td>Brother</td>
<td>-8 days</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>PREOP08</td>
<td>F</td>
<td>28</td>
<td>Son</td>
<td>-15 days</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>POSTOP01</td>
<td>M</td>
<td>45</td>
<td>Son</td>
<td>2 years</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>POSTOP02</td>
<td>M</td>
<td>54</td>
<td>Son</td>
<td>12 years</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>POSTOP03</td>
<td>M</td>
<td>44</td>
<td>Brother</td>
<td>6 years</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>POSTOP04</td>
<td>M</td>
<td>37</td>
<td>Father</td>
<td>1 year</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>POSTOP05</td>
<td>F</td>
<td>70</td>
<td>Husband</td>
<td>1 year</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>POSTOP06</td>
<td>M</td>
<td>53</td>
<td>Daughter</td>
<td>2 years</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>POSTOP07</td>
<td>M</td>
<td>62</td>
<td>Wife b</td>
<td>23 days</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>POSTOP08</td>
<td>M</td>
<td>46</td>
<td>Brother</td>
<td>12 years</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>POSTOP09</td>
<td>F</td>
<td>59</td>
<td>Husband</td>
<td>18 days</td>
<td>Yes</td>
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<tr>
<td>POSTOP10</td>
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<td>46</td>
<td>Husband</td>
<td>1 year</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>POSTOP11</td>
<td>M</td>
<td>50</td>
<td>Friend b</td>
<td>16 days</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>POSTOP12</td>
<td>M</td>
<td>40</td>
<td>Son</td>
<td>9 years</td>
<td>No</td>
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<tr>
<td>POSTOP13</td>
<td>F</td>
<td>67</td>
<td>Husband</td>
<td>10 years</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>POSTOP14</td>
<td>F</td>
<td>44</td>
<td>Cousin</td>
<td>1 year</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>POSTOP15</td>
<td>F</td>
<td>53</td>
<td>Sister</td>
<td>6 years</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

* Paired exchange; †3 way swap
* This donation did not go ahead due to the recipient receiving a transplant through the deceased donor waiting list

### Main themes

Eight primary themes were identified following framework analysis (Table 3.2). The thematic and explanatory analyses are discussed for each primary theme and its relevant subthemes below. Quotes are in italics and given in speech marks with the participant identifier placed at the end of each quote. A conclusion is given at the end of each theme, summarising the findings as appropriate and identifying the potential predictors of outcome that could be measured within a quantitative study through the use of existing or new questionnaire tools.
<table>
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<th>Subthemes</th>
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<td>Impact of disease on the Donor</td>
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<td></td>
<td>Impact of disease on others</td>
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<td>The Caregiver Role</td>
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<td></td>
<td>Donor-Recipient Relationship</td>
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<td></td>
<td>Donor Background</td>
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<tr>
<td>2. Becoming a Living Donor</td>
<td>Decision Making</td>
</tr>
<tr>
<td></td>
<td>The desire and stimulus to donate</td>
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<td></td>
<td>Feelings towards donation</td>
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<td></td>
<td>Discussions with Others</td>
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<td></td>
<td>Anticipated Regret</td>
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<tr>
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<td>Approaching the recipient</td>
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<td>Recipient Response</td>
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<tr>
<td></td>
<td>The Response of Others</td>
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<td></td>
<td>Other potential donors</td>
</tr>
<tr>
<td></td>
<td>If donation could not go ahead</td>
</tr>
<tr>
<td>3. Hopes and Benefits</td>
<td>The Recipient</td>
</tr>
<tr>
<td></td>
<td>For self</td>
</tr>
<tr>
<td></td>
<td>For others</td>
</tr>
<tr>
<td>4. Donor workup, Risks and Worries</td>
<td>Issues at the time of workup</td>
</tr>
<tr>
<td></td>
<td>Consideration of Risks</td>
</tr>
<tr>
<td></td>
<td>Worries</td>
</tr>
<tr>
<td>5. Recovery from Surgery</td>
<td>Donor recovery</td>
</tr>
<tr>
<td>(Post-Operative Donors only)</td>
<td>Recipient recovery</td>
</tr>
<tr>
<td></td>
<td>Recipient Recovery – Impact on Donor</td>
</tr>
<tr>
<td>6. Regret</td>
<td></td>
</tr>
<tr>
<td>7. Life after the Transplant</td>
<td>Donor-Recipient Relationship</td>
</tr>
<tr>
<td>(Post-operative Donors only)</td>
<td>Expectations of the Process</td>
</tr>
<tr>
<td></td>
<td>Expectations of the Recipient</td>
</tr>
<tr>
<td>8. Donation as a life event</td>
<td>Changes in self</td>
</tr>
<tr>
<td></td>
<td>The views of others</td>
</tr>
<tr>
<td></td>
<td>Donation as a life event</td>
</tr>
</tbody>
</table>
Main Theme 1 – Circumstances of Donation

Recipient Circumstances

Recipients ranged from three to sixty-eight years in age. The time between diagnosis of renal failure to transplantation was very broad, from a few months to over ten years. For the donors, this also meant the time between initial discussion and their subsequent workup varied broadly. Transplantation was deferred for a number of reasons, principally because of the recipient's health or other living donors being considered first. Less common circumstances included blood group incompatible transplantation becoming feasible and the death of a family member leading to the recipient not wanting to proceed. All paediatric recipients received a kidney from a parent and it was in this group mostly that additional procedures were necessary prior to transplantation:

“...we knew we couldn’t do it straight away anyway because Great Ormond Street weren’t ready to let my son have the transplant until his bladder was safe...” (Pre-op 08)

“...he had lots of complications [from meningitis]... he had an operation to tidy up his finger... a skin graft on his knee...” (Post-op 01)

All parental donors had experienced at least one episode where their child’s health had deteriorated acutely, all prior to receiving a diagnosis of renal failure. This was associated with very vivid memories of the experience and emotions felt at the time:

“...it was so awful... I thought he was going to die that night...” (Pre-op 03)

“...he was a normal, healthy child until he got struck down with meningococcal meningitis... [we] didn’t realise at the time how serious it was until the next day when he was in intensive care, when we realised he might die... that was a pretty awful time really... we really thought he was going to die...” (Post-op 01)

“I was absolutely petrified of standing at the side of a grave looking down at one of my own children” (Post-op 06)

Similar emotions had also been experienced by those donating to adult recipients who had also spent time in intensive care:

“...they said she was in a life threatening situation... and for literally two weeks they were basically fighting for her life...” (Post-op 15)

“he seems to go into hospital on average twice a year and each time is worse, he seems to get closer to death each time... especially the last time he was in... that was really quite upsetting...” (Pre-op 05)
Renal failure was caused by a variety of disorders; either a primary intrinsic renal pathology or secondary to another disease process. For some, the diagnosis was delayed either because symptoms were not interpreted correctly or the diagnosis was missed. Some recipients had a congenital defect detected antenatally, shortly after birth or years into their childhood. A delayed diagnosis was associated with feelings of guilt and frustration, which in turn had made the donation a form of retribution:

“...if it was caught in time we would not have got to this stage...it’s just really frustrating the fact that it wasn’t caught earlier... [Donation means] I’m able to do something good for him because I do feel very guilty... [I] let them fob me off and I think I shouldn’t have let them...” (Pre-op 08)

The recipients were a mix of dialysis and pre-dialysis patients, some of whom had been previously transplanted with either a living or deceased donor kidney. Some recipients had spent time on the deceased donor waiting list without receiving an offer:

“...he had been on the transplant list for a couple of years...” (Post-op 04)

“...[recipient] did put her name down on the waiting list but... she’s a very rare blood and tissue type, so they said the chances are going to be really slim... ”(Post-op 05)

Impact of disease on the Recipient
Renal failure had affected recipients across all areas of their lives: physically, socially and psychologically. Physically, recipients were perceived to be affected both by their appearance and their symptoms:

"Well he’s a lot smaller than the other kids in his year...” (Pre-op 06)

"I have just seen him getting worse really, all puffy in the face, looking very tired”. (Pre-op 03)

“He always felt cold... first thing in the morning he would get up sit in the chair and then he would be off to sleep... He couldn’t walk very far...” (Post-op 05)

Donors also reported that those on dialysis suffered physical and social restrictions on their lives:

“It just took so much time from his life, from our lives when he had the home dialysis... he couldn’t cope with it, he hated it, absolutely hated it”. (Post-op 13)

“This dialysis it just takes up everything really; 4 hours 3 times a week...” (Pre-op 05)
Donors felt that recipients suffered social consequences as a result of repeated hospital admissions and appointments, symptoms and the unpredictability of their condition. Many recipients also required a family member to adopt the role of primary caregiver.

“...she wasn’t able to attend mother’s funeral because she was in hospital” (Post-op 15)

“...he missed quite a lot of school...” (Pre-op 01)

“...unfortunately the illness has actually become a barrier between him doing what he wants to do in life and going places because it’s unpredictable” (Pre-op 07)

“...I went from virtually not seeing them to full time dad... (Pre-op 02)

Renal failure was also observed as having affected personal and intimate relationships:

“...to have a wife and a child and get married and so on, it’s been one of his dreams because he has never had these sorts of things...” (Pre-op 07)

“I think the sad thing is that children may not be an option now because [his partner] is now 43” (Pre-op 01)

“I mean I can remember her saying to me a few years ago, I am so exhausted... I don't feel like sex and all the things like that was having an impact [on her marriage]” (Post-op 14)

Renal disease was perceived to have had a large psychological impact on the recipients, many of whom were frustrated, angry and unhappy. Many recipients appeared to suffer with low mood as a result of their illness:

“...he is a very miserable person... I could see it was affecting him and I could see how let down he was...” (Pre-op 05)

“...he hated it [dialysis]... and got further and further depressed about it...” (Post-op 13)

Donors felt that recipients found it difficult to talk about their illness and subsequently would choose not to discuss it with others. This was especially common in young, male recipients:

“...he never really talked about it... people genuinely had no idea, and these were the people he lived with” (Pre-op 02)

“I think he just hates generally talking about his illness... he had never said a word to anyone. No one knew so he just likes to pretend it’s not there.” (Pre-op 03)
The transplant was viewed as a necessity; to improve the recipient’s quality of life and to prevent events that were viewed as inevitable, such as dialysis and death:

“I don’t want him to go through [dialysis]. I really, really don’t... I am not going to let my kid go through that” (Post-op 02)

 “[Recipient] had had some problems on dialysis... Then she decided she wanted to go into palliative care... I couldn’t see someone at 45/46 going into palliative care.” (Post-op 11)

“... I actually thought she was going to die if she didn’t get her operation” (Post-op 15)

“[If he doesn’t have a kidney he will be on dialysis, not able to work, his life would be awful and he is at that age where it is so important that he is building his life up... I would like to give him my kidney so he can carry on and have a life.” (Pre-op 02)

Impact of disease on the Donor

Donors whose recipients had become unwell very quickly, and those who had spent time in intensive care, had the most vivid memories of that time:

“...life was very very difficult...” (Pre-op 03)

“... [it was] incredibly upsetting... very scary...” (Post-op 12)

“It was a terrible time for us... it was awful... very very traumatic...” (Post-op 15)

The impact of recipient illness was most dramatic and profound for those who were more involved with the recipient as they too were restricted physically, socially and psychologically by their recipients’ illness. This was especially so for those who lived with the recipient, spent a lot of time with them or who had a primary caregiver role:

“He was such a worry... having a chronically sick child it really is hard and I think, yeah, we did suffer quite a lot really for all those years” (Pre-op 03)

“I have been more limited lately just because I spend a lot of time with [Recipient], he can’t get out much... in a sense I feel like I am not doing enough with my life either... I suppose I would feel a bit selfish going ahead and just doing things on my own...” (Pre-op 05)

“He couldn’t walk very far... if I went out for a walk he wouldn’t come with me so it did make an effect on our lives really.” (Post-op 05)

Psychologically the recipient’s illness preoccupied the donor and their family and was a source of stress. The recipient was typically made a priority in family life, which in turn had impacted on relationships with spouses and other children:
“Day and night I worry about my brother...” (Pre-op 07)

“[it is] all we ever talk about. Even at home my husband, relatives who phone, everyone we talk to it’s about [recipient]...” (Pre-op 08)

“...one of us was at home and one of us were in the hospital. We swapped over. Every day I went to London and every day I would come back in time to pick the little ones up from school, he would go up to London... you really want to be [in the hospital] as much as you possibly can.” (Pre-op 03)

Donor social activities had also been restricted by the recipient’s illness:

“...when [recipient] got ill we had just redecorated our house, got a market appraisal, we were about to sell it, move into a bigger house, so that had to go on hold whilst the income stopped...” (Pre-op 08)

“We couldn’t take holidays, we couldn’t go anywhere.” (Pre-op 03)

Where relationships had broken down, the recipient’s illness had, in part, reunited the family and in some circumstances had improved things:

“We have never really had difficulty dealing with [recipient]'s condition together. We have trouble dealing with each other but not when it comes to [recipient], not at all, it's always him first.” (Pre-op 06)

“We were both united in grief... it has brought us closer together...” (Post-op 01)

“My dad and I have a very bad relationship... the first time he spoke to me was after 4 years when [recipient] got ill and he came to see him in the hospital” (Pre-op 08)

Impact of disease on Others

The primary concern for parental donors was the impact of the recipient’s illness on their other children:

“There was a lot going on with the [other] three children... the impact on everybody's life is enormous...” (Pre-op 03)

“...we didn’t want the other two children to see him [in intensive care]... they were sort of fobbed off with other people...” (Post-op 01)

“...he [youngest son] spent a lot of time away from me with his grandparents and even now he doesn’t get as much attention so he is very naughty...” (Pre-op 08)

Sibling donors also recalled the impact of their recipient’s illness on them as children:

“I was actually always going to see my brother in hospital after school and you know we, as a family, have got used to over the years. It's second nature to us.” (Pre-op 07)
“...he was definitely different to what other kids would be doing... as a child I used to be very envious of [the recipient spending time in hospital]... I guess when I was very young I didn’t really understand...” (Pre-op 01)

The Caregiver Role

The caregiver role was adopted by parental donors, siblings and spouses. The role of caregiver impacted donors’ lives considerably as it was emotionally very difficult and physically and socially restrictive. Many felt that their lives were on hold, either through active caring tasks or by being the “go to” person in the event of an emergency, which in turn caused a lot of anxiety:

“[It was] stressful to say the least” (Post-op 06)

“...having a chronically sick child it really is hard... we did suffer quite a lot really for all those years. [Even now] I am... the first port of call if something goes wrong... if he has to be dialysed I am going to be driving there three times a week and looking after him... [it] would be lovely to have that worry removed from life” (Pre-op 03)

“I was taking [driving] lessons... [but I] can’t leave [recipient] with anyone because... [husband] doesn’t want him left, so my lessons stopped” (Pre-op 08)

“You know you can’t just plan to go to your children for 4 days or on a visit... suddenly these things are not possible so it does affect their whole life really, everybody’s life but in particular ours...” (Post-op 09)

Donor-Recipient Relationship

All donors reported a positive relationship with their recipient:

"We’re on friendly terms. We don’t fall out... I assume we’re like any other siblings... We’ve got a strong relationship, deep down." (Pre-op 01)

“...we are a very close knit family and we take care of each other as much as possible... we talk about anything and everything really. There are no secrets...” (Pre-op 07)

"We are very good friends” (Pre-op 03)

“...he’s a bit like an older brother really in a way and it’s quite nice.” (Pre-op 05)

Donor Background

Many donors had previously experienced other difficulties in their own lives, separate to their recipient’s illness, which had caused them psychological strain:

“...my daughter died from an eating disorder very suddenly. She was dead in bed one morning; it was all terribly traumatic... My younger son had a lot of trouble... various substance abuses, which got much worse after my daughter died.” (Pre-op 03)
"My dad and I have a very bad relationship because I married my husband and he didn't agree with it so he didn't speak to me for years" (Pre-op 08)

"We had our older [daughter], she was constantly getting into trouble with the police, running away from home, drugs, drink, you name it... we had a house fire lost everything... Money worries, my mum died, it was just a really stressful time... one thing on top of another" (Post-op 06)

Religious beliefs were mentioned by a small number of donors:

“...we all have a very clear Christian faith...” (Pre-op 02)

“God touched my heart to do it [donate]...” (Post-op 10)

“...my grandmother... believes in reincarnation, so when you are reincarnated you will be born without one kidney that is what she was telling me... I just ignored her” (Pre-op 08)

Donors themselves had experienced mental health problems including obsessive compulsive disorder (OCD), depression or low mood and alcoholism:

“I did say to one of the nurses... [that] I was feeling a bit depressed... I had to go and see a psychologist... it was nice that that was taken seriously...” (Post-op 03)

“I've always liked a drink... [I've] had brushes with depression...” (Post-op 12)

“I've never taken it [symptoms of low mood] to the doctors... [had previously experienced suicidal thoughts] daily” (Pre-op 06)

“...years ago I had OCD... one of my concerns [was whether] the anxiety related to this operation and what happened afterwards might trigger the OCD or bring it back and it has done...” (Post-op 07)

Summary and Conclusions – Circumstances of Donation

This theme has recognised a number of issues affecting living kidney donors. The recipient’s illness can have a major impact on the potential donor, family and friends. Recipients are perceived to be unwell and their illness or current treatment (i.e. dialysis) has a severe negative impact on them. Those donors who spend a large amount of time with their recipient, for example those who care for, live with or socialise regularly with their recipient, encounter similar social and psychological effects from their recipient’s illness, and some similar physical restrictions. This has implications on their own lives which are inevitably affected. Donors may therefore suffer with low mood, anxiety, stress, low quality of life and low life satisfaction.

In addition, donors experience a spectrum of emotions towards their recipient’s illness including guilt, anger, worry and fear. Acute deterioration in the recipient’s health and
admission to intensive care is a traumatic event and is associated with fears for the recipient’s life. The emotions associated with that time remain vivid and at the forefront of the donor’s mind. These emotions are subsequently carried through to the living donation decision making process and many therefore perceive transplantation as a life-saving procedure. For some donors, having a relative or friend with renal failure is one of many difficult life events, some of which occur concurrently. These donors may suffer with additional stress or other psychological difficulties, depending on which personality traits they have or their coping strategy. Some individuals may require additional support throughout their workup, around the time of donation and during their recovery.

A number of potential predictors of outcome were identified from this chapter. Recipients who are perceived to be more affected by their illness may be expected to gain most from transplantation. As a result, donors may expect to see a greater amount of change in their recipient post-operatively and the extent to which these expectations are met could have an impact on donor recovery. Donors with more involvement with the recipient (i.e. those who live with or care for their recipient) may benefit more from donation as the impact of the recipient’s illness on their own lives is more pronounced. They too seek to benefit from the recipient receiving a transplant and consequently their lives should also improve after the donation has taken place.

A number of the validated questionnaires used in the longitudinal study came from this theme. Validated measures capturing mood (distress and depression), stress, anxiety, quality of life and life satisfaction were included pre- and post-operatively to see whether donation and subsequent transplantation lead to an improvement. Donors were asked about their recipient’s dialysis status and whether they had previously been transplanted. They were also asked if they were the main caregiver of their recipient and whether they lived with them at the time of the donation. Questions related to expected benefits to themselves, the recipient and others around them were also asked pre-operatively and then repeated post-operatively to see if their expectations had been met.

**Main Theme 2 – Becoming a Living Donor**

**Decision Making**

The decision to become a living donor was most commonly made instantly:
“...it was a no brainer really...” (Post-op 01, Post-op 09)

“...[it was] the most simple decision I have ever made in my life.” (Post-op 11)

“I didn’t even think twice about it... I honestly, truthfully, with hand on my heart I don’t think I even thought about it.” (Post-op 13)

Those who did not make their decision instantly had thought about it for either a short time afterwards or had struggled with making a decision for a variety of reasons:

“...the two obvious potential donors were my wife and myself... he is my son, it’s as simple as that...” (Pre-op 02)

“...I just did what any parent would have done I think. I can’t believe that any parent wouldn’t do the same for their child...” (Post-op 01)

Parental donors frequently saw donating a kidney to their child as a natural extension of their parental responsibility and considered themselves and their co-parent prior to any other potential living donor:

“...My wife was already 4 months pregnant... the timings couldn’t really have been worse... I did have to go away and think very long and hard about whether it was appropriate.” (Post-op 04)

“Well it wasn’t a gut reaction... I suppose because I knew it wasn’t just [recipient]’s quality of life that would be improved it would be mine as well... from a purely logical point of view, it was going to be the best solution” (Post-op 07)

The desire and stimulus to donate

Donors had a mixture of feelings about how strongly they wanted to be the person to donate:

“I kind of bullied her... [I said] ‘no, look I am going to go first, I am going to do it’.” (Post-op 02)

“I don’t think I had made my mind up that it would be me but it was always a case if it needs to be me then I haven’t got a problem.” (Pre-op 06)

Some felt that they knew from the very beginning that they would end up donating, either because they would be the best match or others would be found to be unsuitable:

“I kind of knew... I thought ‘I am going to be a perfect match’... ” (Post-op 14)

“I think I have always known... that I was the likely donor.” (Pre-op 02)
For those without an overwhelming desire to donate, a practical and thoughtful approach was adopted with the priority being placed on the tissue type match:

“... [We] agreed that whoever was the best match would donate...” (Pre-op 01)

The main stimulus to donate was the health of the recipient and the fear of what may happen should the transplant not take place:

“...he was very poorly and I think that was more than enough stimulus ...” (Pre-op 01)

“I was absolutely petrified of standing at the side of a grave looking down at one of my own children.” (Post-op 06)

“If he doesn’t have a kidney he will be on dialysis... his life would be awful...” (Pre-op 03)

For some, the behaviour and actions of others was the stimulus:

“...it had crossed my mind... when other people were [going for tests]... after the second time it fell through... I couldn’t really see plausibly who else was going to step forward and do it and just thought someone needs to do it.” (Pre-op 05)

“...my parents put themselves forward first and they went through the relevant procedures but unfortunately it wasn’t convenient due to medical reasons... so my brother approached me...” (Pre-op 07)

Less frequently, other life events had also provided a stimulus. More exceptionally, the idea was believed to come from God:

“I was feeling that through losing my mum, wondered what it would be like not to have my sister around... I just kept imaging what life would be like without her...” (Post-op 15)

“...God touched my heart to do it...” (Post-op 10)

Feelings towards donation
A number of positive emotions were associated with donating:

“I am glad it is me" (Pre-op 06)

“It makes me feel proud...” (Pre-op 08)

“...when it sunk in it was going to be me that was helping him... I thought ‘I quite like that idea’” (Post-op 01)
Donors preferred to be the donor over having to watch someone else go through it. It was acknowledged that the day of surgery would be or had been a stressful experience for others:

"I do prefer [it being] me because then I know I’m not causing anyone else trouble. I am not putting anyone through that 1 in 3,000 risk" (Pre-op 06)

"[Having her daughters donate] was something I didn’t want really… [Recipient] wouldn’t have been happy accepting kidneys from them either" (Post-op 05)

A selection of donors felt very instinctive about being the donor, remarking that it felt right, natural or normal. Some also made reference to a sense of duty and responsibility:

"It seems fine because it is my baby… just such a natural thing for me to do... ” (Pre-op 03)

"...it’s my responsibility [as her Father]" (Post-op 06)

"[It] may be a subconscious extension of my usual role [within the family] and my sense of responsibility [towards his siblings]" (Post-op 08)

“You know you gotta do the right thing haven’t you? I felt as if there was no way out of it... because of common sense, logic and moral obligation” (Post-op 12)

The decision to donate was most commonly made with certainty, determination and following little discussion with others:

“I am very impulsive and once I have made my mind up there is nothing anybody can do to change it” (Post-op 13)

“I was adamant for some reason. I thought ‘I want this to be me. I am going to do this’” (Post-op 14)

A number of negative feelings were identified, principally fear:

“I do feel quite petrified at times” (Pre-op 07)

“I was scared. I never thought I don’t want to do it” (Post-op 09)

**Discussions with Others**

Discussions between the donor and their loved ones varied broadly from an in-depth discussion to no discussion at all:

“...[The family] had an open discussion...” (Pre-op 04)

“...it would always have been very wrong for me not to have discussed [it] with my wife...” (Post-op 04)
“...you know we didn’t really discuss it... No not discussed. I have told them.” (Pre-op 03)

**Anticipated Regret**

Donors were not concerned by what others would think of them had they chosen not to donate. Feelings of anticipated regret (feeling regretful if they did not donate) were motivational for some:

“I just kept imagining what life would be like without her...” (Post-op 15)

“I couldn’t live with myself [if I didn’t donate]... It would be too painful... just be too unbearable.” (Pre-op 07)

“...the major regret would have been seeing the continuing deterioration of my father and the impact on my mother... that would have kind of washed around the rest of the family too. I think ultimately that would have been my main regret.” (Post-op 04)

Anticipated regret was not a motivator for donors in cases where feasible alternative management options were available:

“[If I didn’t donate] I suppose [he] would have to have had one of the other options...” (Post-op 03)

“...the one thing we learnt is that you always have to have a plan B... we would move to a house that we knew we could convert and have a dialysis room...” (Post-op 02)

**Approaching the recipient**

Donors most commonly offered to donate rather than being asked by the recipient:

“I said I will be a donor...” (Post-op 13)

“I said tell her not to worry she could have one of mine” (Post-op 14)

“He never asked...” (Post-op 05)

Many donors felt that their recipient would never have asked them to be a donor:

“He wouldn’t have asked me...” (Post-op 13)

“It’s not in his nature [to ask]” (Post-op 08)

Parental donors commonly did not discuss donation or formally offer their kidney, regardless of the age of their child:
“...there was no formal agreement made but I think there was just that general assumption” (Pre-op 02)

“When you are a child you kind of expect your parents to do that... I don’t think he would consider that I wouldn’t do it and so we never discussed it.” (Pre-op 03)

Recipients who had asked their family to donate focussed either on one individual or the family as a whole:

“...we got back in the car [after a hospital appointment] and just out of the blue said ‘how do you fancy being a donor?’” (Post-op 09)

“As far as I can remember he got us all together, we went to the pub one evening... I can't remember his specific words but it was obvious that was what he was asking.” (Post-op 03)

The few donors who were asked directly to donate by their recipient in a one-to-one setting felt pressured and a sense of urgency to say yes without having time to think about it. This was associated with anxiety and feelings of entrapment. Those who were asked as part of a group felt more able to withdraw from the process had they wished to:

“... [she was] lying in intensive care at the time and it wouldn’t have been a very wise thing to do to say 'oh no I’m not [donating]'” (Post-op 07)

“...it was just like a passing comment, 'how do you fancy it?' and I honestly can’t remember what I replied but certainly wouldn’t have said no... it's afterwards you think of the implications... I would have felt very trapped [had she wanted to change her mind]” (Post-op 09)

“I think it would have been easy to say to him [had he changed his mind]” (Post-op 03)

Recipient Response
Both positive and negative recipient responses were experienced. The negative responses varied on a spectrum of the recipient being unexpectedly underwhelmed to outright refusal:

“[he responded] very positively. I think it was a nice... he reacted really well” (Pre-op 01)

“[He] was quite dismissive really... I did think at the time that that was a little bit ungrateful...” (Pre-op 05)

“[He was] very grateful for the offer but dealt with it in a typically male way by not showing his emotions much” (Post-op 08)

“I think he nearly dropped off the chair. He just said ‘no I don’t want you to be’ [a donor]...” (Post-op 13)
The Response of Others

A broad range of responses were experienced across both familial and non-familial relationships. Donors’ mothers had the most negative familial responses. Concerns related to the operative risks were consistently perceived to be greater for the donor than the recipient; even though the risks of the recipient operation are higher:

“...my mother was absolutely petrified... she said ‘I think you are raving mad’” (Post-op 13)

“...she found it quite difficult... she’s stuck between a rock and a hard place seeing one of her children do this and then her husband needing it as well.” (Post-op 04)

"My mother is horrified, absolutely horrified.” (Pre-op 03)

Donors’ fathers were reported as being more positive about donation. It was acknowledged that they were likely to be as concerned, however less vocal:

“My dad has been generally quite positive about it. I don't know what his actual opinion is ...but from what he said he has been positive” (Pre-op 05)

“I mean my dad was just sort of said ‘my god you are amazing, such a brave thing to do’” (Post-op 01)

The responses of donors’ children were varied both amongst individual families and also when the recipient was a co-sibling. Negative responses were interpreted by donors as the child being worried:

“...the only one I did worry about was [youngest daughter] a little bit because she doesn't express herself that much... my eldest son was very positive...” (Post-op 14)

“My son [said] ‘well why would you do something like that?’... He [thinks] it’s absurd... which is funny really because he knows [recipient] is so ill... maybe it’s just because he worried about me” (Pre-op 03)

Donors’ spouses were consistently supportive but anxious, especially when the recipient was also their child. Extended family, friends and colleagues were most positive and least concerned about the risks:

“[Donor's wife] fully accepted why I wanted to do it..." (Post-op 04)

“He [husband] is terribly anxious. He is the worst, absolutely terrible white, can’t sleep, can’t do this, terrible. Yes he is really frightened... Is he more worried about me or [recipient], I don’t know... “ (Pre-op 03)
“I didn’t even think about work I mean basically I was to go to have the time off and that was that” (Post-op 15)

Donors varied on how many people they had told about their donation. Donors’ employers were commonly informed out of necessity:

“…we didn’t tell our dad until I think a couple of days before” (Post-op 15)

“…it was quite a sort of personal thing between us... I didn’t say that I was donating until I had to…” (Post-op 11)

Extremely negative views were more exceptional and in some circumstances led to arguments:

“He said to me ‘have you thought about this?’... He said ‘I think you are raving mad... you are putting your life [at risk]’... I told him... ‘it’s got nothing to do with you’...” (Post-op12)

“...I have fallen out with a couple of [friends]...” (Pre-op 05)

Some donors experienced mixed views from their friends, some of whom commented that they were in support of the donor but would never donate themselves. Positive findings were comforting whilst negative responses were associated with negative emotions:

“People sort of like said ‘oh it’s very valuable what you are doing but we wouldn’t do it’... the negatives were very depressing...” (Post-op 11)

“...people around me kept saying how brave I was and that was very comforting, it made me feel good...” (Post-op 09)

“Some of my friends are like ‘that’s the best gift you can give to your son’. It makes me feel proud...” (Pre-op 08)

Other potential donors

The number of alternative donors available varied considerably, as did the extent to which other donors had been pursued and subsequently investigated. Relatives who had not considered donating or had withdrawn an offer to donate (for a range of reasons) were viewed as selfish and inconsiderate:

“I was the only one that could donate” (Post-op 08)

“She’s got about 8 brothers and sisters. I mean unfortunately there seems to a sort of trait in her whole family of being totally selfish... [they] just weren’t interested” (Post-op 11)
"My wife and I both went forward for tests and my wife was found to be the perfect match... She [then] had a series of strokes and she couldn’t do it” (Post-op 06)

Being the only potential donor was associated with increased stress and anxiety during the workup process. This was because being found unsuitable would leave the recipient with no prospect of having a living donor transplant. For parental donors the main alternative was their co-parent, who was commonly also tested. Having alternative donors available was comforting, reassuring and helped decrease the level of stress:

“I was thinking what if I’m not healthy enough, what if I have only got one kidney... I was really stressed... panicky and scared and was thinking well what are we going to do? ...I knew that his family are not an option and I knew I wouldn’t ask my family... [I was] really worried...” (Pre-op 08)

“I think the fact we’ve got those other people behind us as well that just gives you that extra reassurance and comfort” (Pre-op 04)

“We had four other members of the family that come forward [saying] that they would do it... And then I thought well if all else fails with me then one of them could go forward” (Post-op 06)

Donors felt very differently about approaching others to donate. Adult recipients with children were commonly reluctant to accept an offer of a kidney from one of their children, preferring a spouse to donate instead:

“No, no we didn’t [ask anyone else]” (Post-op 12)

“I think it would have been fairly easy because they have always volunteered” (Pre-op 06)

“No we didn’t [think about asking anyone else]... there was no deliberate thinking of a plan B... but we most definitely [would have asked others]...” (Post-op 02)

“[Recipient] was less keen on the girls, the daughters... he wouldn’t have been happy I don’t think accepting kidneys from them. I think he would have felt a bit guilty” (Post-op 05)

If donation could not go ahead
A number of donors had never contemplated the transplant not going ahead prior to being asked in the interview. There were a number of emotions associated with the prospect of not being able to donate:

“I’d have felt very disappointed... and I think there would be an element of letting someone down or people down as well. So there would be a lot of regret....” (Pre-op 01)
“I would have been really devastated because I had set my mind [on it]... I would have been really really upset... I would have felt a bit of a failure really I think” (Post-op 05)

The principal concern was for the recipient and consequently, those donors who were the only potential donor to their recipient were most distressed by the prospect of not donating [See “Other potential donors” above].

**Summary and Conclusions – Becoming a living donor**

The key finding from this theme was that the decision to become a living donor is typically made instantly, without the donor being fully informed of the potential risks. As a result, the thought process behind it is difficult to dissect. The decision to donate is fixed and not wavered by donors’ fears related to the risks of surgery or when faced with negativity from others. Donors referred to their personality when considering their decision making, most of whom considered themselves to be decisive people. These donors also appeared to be more emotional about their desire to donate, feeling passionately that this was what they wanted to do. Those donors who did not make their decision instantly were more rational in their decision making, weighing up the pros and cons of donating versus not donating. All donors who had thought about donating before making their final decision had considered the benefit to themselves and the benefit to other members of the family, as well as the recipient who remained the main motivating factor.

Anticipated regret was also part of the decision making process. Donors were not concerned about what people would think of them should they not donate, but rather they wanted to avoid the negative emotions associated with watching their recipient become more unwell or die. Some felt desperation at the way their life was currently, or what it would be like should the recipient require dialysis. Donating was a means to avoid these feelings of despair. Feelings of desperation were more pronounced in those who were their recipient's primary caregiver. The emotions related to the possible death of the recipient were more pronounced in those whose recipients had been admitted to intensive care; where commonly there were concerns at the time that the recipient may not survive. Donors recalled these experiences very vividly and the trauma and emotional upset associated with them was very evident, even after many years.
Donors most commonly offered to donate their kidney; an offer which was warmly received by the recipient. Where recipients refused or tentatively accepted the offer, concerns were principally related to the risks the donor would face on their behalf. Parents resisted accepting a kidney from one of their children. Being asked to donate was associated with an immediate response to say yes; possibly because the donor saw the recipient's request as a test of their love for that person. It was also associated with feelings of entrapment; that they would not be able to withdraw from the process easily should they wish to and that the decision had been made for them. The size of the potential donor pool was also an important factor. Those donors who were the only potential donor to their recipient experienced more stress and anxiety than those who were one of many, as there was more resting on them as an individual.

Negative reactions from others were also associated with increased stress and anxiety and, at times, had led to intense arguments between donors and their families. Concerns came predominantly from donors' mothers who were very worried about the risks of surgery. The risks of surgery for the donor were consistently more troublesome to family members than the risks to the recipient, even though the recipient operation is associated with higher risks. This is possibly because for the recipient, family members are able to offset the very obvious risks of surgery against the equally obvious benefits. For the donors, families are unable to offset the very obvious risks of surgery against a physical benefit and, similarly to the transplant community, are uncertain of how the donor will benefit from their donation and whether the risks will be justified.

This theme identified the importance of measuring social support, both generally and for the donation process. Donors commonly referred to their personality, which was also measured to see whether donors were associated with particular personality traits. New questions were written to capture how the decision to donate was made, how much the donor was driving the donation, whether they offered or were asked to donate and whether there were any other potential living donors.

Main Theme 3 – Hopes and Benefits

When contemplating the hopes and intended benefits of living donation, attention was focussed primarily on the recipient. Expectations of how the recipient's life would change were high. The benefits to self and others within the family and immediate social network were also discussed.
The Recipient

Health

Donors hoped that many of their recipient’s symptoms would resolve following transplantation and that they would look and feel better. Many donors referred to wanting the recipient to be ‘healthy’ again or to return to ‘normal’. The use of these terms was surprising given the recipient’s lifelong dependency on immunosuppression medication, the risks and side effects associated with them and the possibility of requiring another transplant in the future:

“I would just like him to feel better, to grow... not feel tired all the time, not have to be hooked up to his machine every night” (Pre-op 06)

“Obviously the main thing is to get [recipient] back to being healthy...” (Pre-op 04)

“My hopes would be that she would be fit and healthy” (Post-op 06)

“My main motivation is that we would have my sister back...” (Post-op 15)

There was a desire to remove the recipient’s dependence on dialysis and subsequently remove the physical limitations and suffering it caused. Life on dialysis was not seen as ‘a life’ but more of an existence. Those whose recipients were yet to start dialysis wanted to prevent dialysis ever being necessary:

“...he is suffering, going to dialysis all the time” (Post-op 10)

“[Dialysis] keeps them going doesn’t it... it just keeps you going... they don’t necessarily feel all that well.” (Post-op 05)

For some, transplantation was viewed as a life-saving or life-lengthening procedure:

“...I was going to save her life because I actually thought she was going to die if she didn’t get her operation” (Post-op 15)

“I was absolutely petrified of standing at the side of a grave looking down at one of my own children... she can also have a long life now where she couldn’t before.” (Post-op 06)

Life prospects

Normality and improving the recipient’s quality of life were the dominant subthemes, with many donors speaking very animatedly about what they hoped the transplant would mean for their recipient. Normality was spoken of consistently, with a ‘normal life’ being considered as one that was free from the limitations of illness. It was hoped that adult recipients would return to how they used to be before they became unwell.
Renal failure had suspended the recipient’s life as they had known it, and transplantation offered an opportunity to pick up from where they had left off:

“He can get on with his life, enjoy his life” (Pre-op 05)

“... [to get] back on the right track...” (Post-op 11)

Paediatric or young adult recipients were commonly compared to people of the same age and donors wanted them to achieve similar milestones and have the same opportunities as children who were well. This was even more so in cases where the child or young adult had been affected by illness from a very young age, as the restrictions and limitations on their lives had been more pronounced:

“[I want him] to be able to sit with us and have something to eat, go to a party and have as much to drink as he wants, run around with his brother... his brother gets up in the morning... and he goes straight to the toys and the books... [recipient sits] on his bed, so patiently because he knows that before he gets up and gets out of bed I have to disconnect him from his dialysis and then he has to have his blood pressure and his temperature taken... he’s got so bad with his eating and his nausea that he won’t even brush his teeth anymore... [we would like] everyday things to become normal again and not to [be] like torture for him...” (Pre-op 08)

“...he has to be a kid... he should be on the street falling off bikes, he should be grazing his knee and coming home crying not with a bag strapped to a door falling asleep. [Without the transplant] he would never have a childhood and for me that’s so key...” (Post-op 02)

“My hopes would be that she would be fit and healthy, she could lead a normal life and perhaps get married, have children, which is what she wanted to do...” (Post-op 06)

Donors wanted their recipient to have psychological freedom from the burden their disease so that they could be happy and enjoy life in a way the donor had seen themselves or others do so:

“...the main point is to actually see my brother smiling again, being happy; enjoying his life... it will be exciting for him” (Post-op 07)

“...just go on living a normal healthy life and maybe smile once in while...” (Post-op 05)

Many recipients had experienced social restrictions, such as not being able to work or travel. Transplantation would allow recipients the opportunity to make independent choices and enjoy new experiences that they had always wanted to pursue:
“...he hasn't spread his wings as much as some 26 year olds might...” (Pre-op 03)

“He would like to travel, which of course he has really not been able to do because of the dialysis, so he has got some decisions to make... it’s the good decisions; striking things off the list rather than having them struck off, as it were.” (Pre-op 02)

Expectations of the Recipient

Pre-operative donors were asked specifically about any expectations they may have of their recipient for after the transplant had taken place. Most commonly donors had no specific expectations but hoped that recipients would embrace the opportunities that having a transplant may give them. Specific expectations were related to behaviour and taking care of the kidney, however donors accepted that ultimately it was the recipient’s choice as to whether to do so:

“Only that he will go and enjoy life, simple as that” (Pre-op 02)

“I have already told him he has got to look after it... He says ‘yes daddy I promise I will’...” (Pre-op 06)

“...I did say... I would be very disappointed if I put myself forward and done this for you and then you did throw it all away ... he knows better than that...” (Pre-op 05)

For self

As noted above [See Circumstances of Donation] some donors had been similarly affected by their recipient’s illness and as a result, sought to benefit in similar ways. Donors had become physically restricted due to the recipient’s dependence on them for day-to-day care and hospital visits. In terms of their own health, the donation workup process had provided reassurance about the quality of their own health:

“I think sometimes I just need to do something else [other than care for the recipient]” (Pre-op 08)

“I see it as limiting my life and taking up a lot of time...” (Pre-op 03)

“I kept thinking to myself ‘you have had the best MOT you could have had’” (Post-op 09)

Psychological and emotional gains were anticipated through the removal of negative emotions, such as stress, worry and a feeling of responsibility, as well as the gain of positive emotions from doing something good and seeing the recipient well:
“I do worry about him... [It] would be lovely to have that worry removed from life... I would like not to feel so responsible for him so that’s a real positive thing for me...” (Pre-op 03)

“You don’t want to have to worry about a loved one who’s sick or poorly and if you can fix it...” (Pre-op 01)

“I would feel great, I would feel relaxed...” (Pre-op 07)

“I suppose you do get a sense of satisfaction that you have helped someone...” (Post-op 11)

Donors anticipated the greatest gains to themselves to be social, especially for those who spent a lot of time with the recipient, those who were the prime caregiver or those who were most emotionally involved. Like their recipients, donors wanted to make more of life and enjoy the freedom associated with the recipient being well:

“I plan to make some changes in my life. I haven’t done up until today present day due to you know like I said family commitments and sacrifices” (Pre-op 07)

“I would get as much out of it as [recipient] hopefully. Yeah it’s for us really...” (Pre-op 04)

“... I knew it wasn’t just [recipient]’s quality of life that would be improved it would be mine as well... we have always enjoyed foreign holidays and it means that we could go and have [one]” (Post-op 07)

“...we want to be able to go spend the winter in warmer climates and we love family in France, travelling ...enjoying our grandchildren...” (Post-op 09)

Donors commonly felt selfish in admitting there were benefits to themselves and often referred to this immediately prior to making a statement about the anticipated benefits:

“... It was selfish in a way but...” (Post-op 05)

“... I guess there is also a selfish part for me as well...” (Pre-op 01)

“...I suppose in a slightly selfish way... we have the benefit of having them healthy...” (Post-op 04)

Pre-operative donors largely did not expect their emotional relationship to change following donation, as they already felt close. No donors wanted their recipient to be overly thankful or feel indebted to them. Donors who did anticipate the relationship with their recipient changing thought it would be for the better:
“It could change... I think if it would change it would change for the better, it would get even better but I can't see it becoming an issue for the relationship” (Pre-op 04)

“Well I hope it won’t change. We are very good friends. I hope he doesn’t feel that I have done something for him so that he owes me something…” (Pre-op 03)

“I will never say to him ‘I did this for you, you owe your life to me’ because when you give birth to them you don’t do that so this is the same thing really” (Pre-op 08)

For others
Benefit to others was not considered by everyone but was factored into the decision making process by some. Donors envisaged the family benefitting emotionally from moving on and from the removal of the stress and worry associated with the recipient's illness. Donors wanted to make other members of their family happy through the recipient being well again. Familial relationships of all kind would benefit; in particular spousal and parental relationships with other children:

“...it was for her that I did it firstly and then the rest of the family [and] the children...” (Post-op 15)

“I thought it would bring people together as well... there was an element of 'I'm doing it for us' about it” (Post-op 12)

“[There is a benefit] to the whole family... it is going to benefit all of us not just [recipient]. It's going to benefit his brother, it's going to benefit me, my husband all of us... because he will be better and... because our lives revolve around [recipient]” (Pre-op 08)

Summary and Conclusions – Hopes and anticipated benefits
Pre-operatively donors held many hopes for their donation. The primary beneficiary was their recipient, followed by themselves and others in the immediate family and social network. As noted above [see Circumstances of Donation] donors and recipients had been affected by the recipient's illness physically, psychologically and socially and it was across these three domains that the benefits could be found. The improvement in recipient health following transplantation provided the passage through which the psychological and social benefits would materialise. This is because the physical limitations were deemed the reason for the resultant psychological issues and social restrictions. Donors wanted their recipient to have the same opportunities in life as those who did not suffer from renal failure. A transplant would remove the physical restrictions that accompanied renal disease (such as dependence on dialysis) and allow more freedom and the chance to make life choices.
Those donors who were most closely involved with their recipient emotionally or who provided a caregiver role spoke more of the anticipated benefits to themselves than those less involved. This was because they had not only been affected in similar ways to the recipient but also, in some cases, to the same extent. Donors commonly felt guilty or selfish in acknowledging the benefits to themselves and had not openly discussed these with anyone prior to the interview taking place. This can be interpreted as donors feeling that their own benefits provided an unacceptable reason for wanting to donate and that the recipient ought to remain the primary beneficiary in order for the donation to be valid.

Although these hopes and anticipated benefits were not commonly discussed within the context of expectations, one was left with the impression that the sum of these amounts not only to high expectations from the transplant, but also from the recipient. This is discussed further below [see Regret and Life after the Transplant]. The anticipated benefits of the transplant appeared to be heavily invested in the recipient’s outcome, rather than an intrinsic benefit to the donor from the act of donation alone.

This theme identified the importance of measuring pre- and post-operative life satisfaction and overall wellbeing. It also highlighted the importance of measuring donor expectations both pre- and post-operatively, and to see whether donors felt that the benefit to themselves was independent to the outcomes in the recipient. New questions were written and asked pre-operatively about the anticipated benefits to recipient’s life, the donor’s life and the lives of others around them. These questions were repeated post-operatively to see whether expectations have been met.

**Main Theme 4 – Donor workup, Risks and Worries**

**Issues at the time of workup**

Donors were most commonly well with no medical or psychological problems identified during their workup. Donors were not worried about having a new medical or surgical problem diagnosed or the implications of such a diagnosis; rather they were more concerned that being diagnosed with a medical or surgical problem would preclude them from donating:

“I was worried each step that I would be rejected” (Post-op 05)
Some donors recalled a history of both formally diagnosed and self-diagnosed mental health problems including alcohol dependency, depression and obsessive compulsive disorder:

“I was carrying it all around for decades... I drink for any old reason really... [after recipient became ill] I did numb myself for a couple of years... I have been through counselling, I have tried to nail things...I did go into a rehab clinic twice” (Post-op 12)

“Over the years I have occasionally had periods when I get depressed” (Post-op 03)

“...some years ago I had OCD” (Post-op 07)

“I have got a fear of choking and having tubes from my throat into my chest... you know what if it gets stuck and you can’t take the tube out ...?” (Pre-op 07)

Psychological support was not offered routinely to all donors and those with subclinical or undiagnosed mental health problems did not recall being asked about their mental health history as part of their workup. Donors with a documented history of mental health problems were asked to see a renal psychologist prior to donating. This was a mixed experience:

“[It wasn’t] particularly helpful” (Post-op 03)

“[The surgeon] got me to see [renal psychologist]... in the run up from October-November up to the operation, which has helped a bit I think” (Post-op 07)

Those donors who had not sought psychological support in hindsight felt it would have been of help to them, both in terms of accepting that they had a problem and also in preparation for their donation:

“I think if you came to me and said ‘right you are depressed you have to speak to somebody or we won’t do the transplant’... [it] would probably work better... I would be more inclined to go and speak to someone” (Pre-op 06)

“[Psychological support] would have helped, yeah” (Post-op 06)

The process of undergoing extensive medical tests was stressful for some donors who had mixed views about the amount of time it took to have everything completed:

“...but it is stressful... all this coming up the hospital, the time off work...” (Pre-op 05)

“...it was so gradual... If it had been really concentrated then I think [recipient] might of got a bit worried” (Post-op 05)
"...quite frankly I wish someone could have said ‘right get in there now, let’s whip it out and then you can get on with your life’... I just wanted to kind of get on with it" (Post-op 14)

Consideration of Risks

Donors consistently did not contemplate the risks of surgery prior to making their decision to donate. This fitted with the instant decision making as discussed above [Main Theme 2 - Becoming a Living Donor]. The risks were discussed regularly throughout the workup process and donors varied in their responses to them. The most consistently held view was that they were unimportant and no donor considered changing their mind having been informed of the risks. Some donors trivialised them and remained comfortable with them throughout:

"...they’re statistics that I’ve been told and that’s about it really... they go in one ear and out the other” (Pre-op 05)

"Yeah I know the risks... It’s not formed part of my decision because I think the risks are fairly minimal in terms of the gains... it’s like going on a plane really” (Pre-op 04)

“"I know there is a risk; there is a risk in anything you do so I am not particularly worried…” (Pre-op 03)

"...you listen to the risks and shrug your shoulders and say ‘well ok yes it’s a risk’ but you just keep your fingers crossed and hope they don’t come to fruition” (Post-op 07)

Some donors stated that they trusted the surgical team taking care of them:

“I’m comfortable with the thought that people know what they are doing.” (Pre-op 02)

“I trusted the surgeons; they know what they are doing” (Post-op 05)

Donors with strong religious beliefs put their faith in God:

“God will guide me lead me and go through everything...” (Post-op 10)

“I thought well to some extent it’s in God’s hands, end of story” (Post-op 11)

The risk of death was the main concern, yet donors varied in how concerned they were by it:

"Well you know risk of death, risk of this, risk of that... there is a risk to everything and they were very minimal...” (Post-op 05)
“...death is the ultimate cause of concern for me... it’s been bothering me like nobody’s business and I am scared and petrified because that is the ultimate, you know, worst case scenario isn’t it?” (Pre-op 07)

When contemplating their own death, donors commented that it would be worth it if their recipient went on to have a functioning kidney and a better life as a result. The detrimental effect on the family was also acknowledged:

“...as long as I know I have given it my best shot and that my, if I do die it’s for a good cause my son will live on and be healthier and happier so you know...” (Pre-op 08)

“If I had died I think that would have been pretty bad for all concerned...” (Post-op 01)

Parental donors cared very little about the risks as they considered their child’s health to be the most important and only relevant outcome:

“... when it’s your child you don’t care, you think if I had to give my heart and stopped living I would do it...” (Pre-op 08)

“As depressing and ridiculous as it sounds I think it’s just I don’t really give a monkey’s what happens to me as long as [recipient] is alright...” (Pre-op 06)

Those who were more concerned about the risk of dying found the immediate preoperative period very difficult and felt unable to talk about their concerns with others:

“[The risk of death] was quite difficult... how can you talk to somebody about dying when you know the chances were slim but it can happen? I know it sounds really stupid, but I was starting to worry [about] what I would want at my funeral...” (Post-op 14)

“I mean I couldn’t hide it; I was a nervous wreck really from the moment we were given the date... [Christmas] felt like the last get together... I wanted the whole family together, almost like in case we die or anything... I was in a foul mood but it was just because I was so worried... I flipped sometimes... I got cross or was worried or ended up in tears... I wanted to have the house just so in case I didn’t come back” (Post-op 09)

In an isolated case the donor recalled not being aware of the risk of death until the day of the surgery. This led to feelings of fear, panic and a last minute rush to see all his family before he went into the operating theatre:

“... [on the day of admission] you meet the surgeon and the first thing he tells you was... that you could die and you sort of think ‘no one mentioned this’... it was[a] shock ‘oh you could die. Is this my last hour or two on earth?’... [I felt like] a soldier going into battle... all the family came up just in case anything happened. I said to my son... ‘if anything does happen I am relying on you to look after the
family’... My father was there, my son was there, [recipient] was there obviously, my wife was there... as I was going down for the operation I tried really hard to keep the tears back so they didn’t see it. [I was worried] that I could die and I am not going to see them again” (Post-op 06)

Some of the other risks of surgery were also mentioned and some were more concerned about these then the risk of death:

“I think the biggest fear was infection” (Post-op 09)

“I got really paranoid about blood clots... because my mum had a pulmonary embolism” (Post-op 14)

“...all types of things cross my mind.... everything really from death to actually thinking is there going to be any health complications... am I going to be physically deformed, all types of things...” (Pre-op 07)

Worries
Donors worried about a broad range of things related to surgery and these were understandably more common in the pre-operative group. Donors were, or had been, concerned about whether they would be suitable to donate and whether the transplant would take place:

“I was thinking ‘what if I’m not healthy enough, what if I have only got one kidney’... I was really stressed and I did feel panicky and scared” (Pre-op 08)

“I was worried each step that I would be rejected” (Post-op 05)

Those who were primary caregivers for their recipient were worried about the recipient being cared for by another person and having major surgery in their absence:

“I am so worked up about thinking about [recipient] and I know what he’s like... I am thinking how his dad is going to cope with him on that day. I know when we get to theatre he will know what is going to happen and he always gets very upset and very stressed out... and my son’s going to go in for this really long operation...” (Pre-op 08)

Concerns about the surgery and immediate post-operative period were most commonly focussed on the recipient and the threat of rejection:

“I just so hope that he doesn’t have any major rejection” (Pre-op 03)

“I’m just hoping that it doesn’t go in and then fail straight away or that the condition comes back and we are back to square one” (Pre-op 06)
… I say my main feelings are what if they take it out of me and then for some unforeseen reason they are not able to put it in [Recipient] and the whole thing ends up being a waste of time; that’s what worries me” (Pre-op 05)

Donors considered their time in theatre, the post-operative stay and subsequent recovery. The most commonly feared symptom was pain and the most commonly feared procedure was catheterisation. Donors also mentioned the ward environment and were concerned about day-to-day tasks such as sleeping in a room with strangers and blood tests.

“… I don’t do pain… and I was worried about it” (Post-op 09)

“None of it really concerns me I’m just not looking forward to the catheter” (Pre-op 06)

“I am a bit anxious obviously, having the anaesthetic. I am not concerned about anything serious happening; it’s just not very nice” (Pre-op 03)

“[There is a] lack of privacy… just being with a load of strangers on a ward I just wasn’t looking forward to it” (Post-op 03)

Donors were also concerned about their families on the day of surgery who they expected to be worried and anxious whilst they were in theatre:

“[My husband] is terribly anxious, he is the worst, absolutely terrible white, can’t sleep, can’t do this, terrible. Yes he is really frightened” (Pre-op 03)

Summary and Conclusions - Donor Workup, Risks and Worries

This theme identified a broad variety in the ways that donor workup was approached by individual donors. In the decision making process the risks of surgery were commonly unimportant and for many were not a concern. Those who did worry found the risk of death the most concerning and the most distressing. It was difficult for donors to discuss their fears with their recipient and their families. Other factors related to recovery, such as being on the ward and having to have certain medical procedures, occupied the minds of some donors more so than the surgical risks. Post-operative worries and concerns focussed primarily on the recipients rather than themselves.

New pre-operative questions were written to ask donors about how concerned they were about the donation process (including the operation, their stay in hospital and subsequent recovery at home) and the social impact of their donation (including childcare, finances and housing). They were also asked how much they worried about
the recipient and things going wrong post-operatively. Questions were also written to ask how comfortable the donor would be in discussing problems or concerns related to their donation (or indeed contemplation of withdrawing from the process) with their recipient, friends and family and with the living donor team. Additional demographic questions were asked including medical, surgical and mental health history, as well as the need for interventions, treatment and time in hospital.

**Main Theme 5 – Recovery from Surgery (Post-Operative Donors only)**

**Donor recovery**

Post-operative donors’ accounts of the day of their surgery and recovery period remained vivid. A range of emotions were experienced on the day of surgery and, on reflection, many donors commented that they only realised the enormity of what they were doing upon arrival onto the ward:

“…I can just remember feeling really nervous and actually going down to the operating theatre I was like ‘oh my God’. I mean that was pretty bad” (Post-op 01)

“I was all euphoric [but] as soon as I went into that ward I thought ‘Ooh’” (Post-op 05)

Experience of donors’ hospital recovery was varied with good, bad and mixed experiences. Expectations were rarely met with those anticipating a terrible experience feeling more positive than those who had given it little thought. Donors who had thought little about the operation and their recovery commented on how much more severe their symptoms were than they had expected:

“I wasn't prepared for how awful I would feel” (Post-op 01)

“I think that I was quite surprised that I was so free of pain” (Post-op 07)

“[I] underestimated how painful it would be” (Post-op 08)

“[Pain] that was quite good actually, I was surprised... it was 10 times better [than expected]” (Post-op 09)

A dominant subtheme in the donors’ recovery was the experience of becoming a patient through the act of donation and the role reversal between the donor and the recipient, with the recipient feeling much worse post-operatively and the recipient feeling much better:
“I didn’t realise it was such a big operation... the next day [recipient] was sitting up in bed and they tried to get me up and I couldn’t get up. I was so shocked when I looked over ... and he was sitting in the bed and he kept saying to me ‘oh come on girl get up’. I couldn’t move...” (Post-op 13)

A more negative psychological recovery was made by some donors and included recurrence of mental health problems, low mood and tearfulness and feelings of vulnerability:

“[OCD has] just crept back again a bit surreptitiously...” (Post-op 07)

“I remember I was sitting in the armchair it was late in the evening... I just burst into tears for about half an hour I suppose, a good cry and after that I was alright” (Post-op 06)

“I just felt very very vulnerable after surgery... I did feel very very sorry for myself...” (Post-op 15)

Recipient recovery

The trajectories of recipient recovery were varied; some had none and some had many complications. Problematic physical symptoms such as energy levels and the need for dialysis were removed and recipients looked instantly healthier. The social benefits anticipated pre-operatively were largely met with recipients being able to eat and drink as they wish, return to work and school and pursue their hobbies and interests:

“[Life felt] back to normal... when he had the tubes out and he could swim again... not having dialysis was the main thing and him being able to go back to school” (Post-op 01)

“... she is back to leading a full life...” (Post-op 14)

“...it’s horrible seeing your vulnerable son with a shadow hanging over him. I don’t see that now” (Post-op 09)

Unfortunately some recipients had experienced complications following their surgery which included graft deterioration, graft loss, deterioration in other medical problems and malignancy:

“...it didn’t work for my sister and that was pretty sad...” (Post-op 15)

“[Recipient] is now partially sighted... as he became diabetic... the kidney is not functioning the way it should... I am upset about that” (Post-op 13)

“6 years ago he had cerebral PTLD [Post-transplant lymphoproliferative disorder] so that was bit... that’s [why] you sort of... still live day by day. When that came along that was like ‘didn’t see that one coming’... I got angry because well ... I was just frustrated” (Post-op 02)
Recipieent Recovery – Impact on Donor

News on the recipient’s recovery and seeing the recipient after the transplant was uplifting in the immediate post-operative period. Donors felt that the process had all been worthwhile and that the recipient was noticeably benefiting from the transplant instantly:

“... the thing that really made it worthwhile is that I kind of got wheeled over to my son... then it kind of really hits home...kind of well you know ‘oh wow, that’s a bit special’” (Post-op 01)

“I can remember the morning, the next day after the transplant. I can remember looking at him in the bed and I could see literally see the difference which was amazing. He just looked 10 years younger... I just wasn’t expecting to actually be able to actually see the difference in him” (Post-op 03)

Summary and Conclusions - Recovery from surgery

Donors had a variety of experiences following their surgery, none of which affected how they felt about their donation. No donors admitted feeling regretful when they were suffering with symptoms post-operatively. Seeing the recipient in the immediate and short-term period was reassuring and made the process appear worthwhile. Few recipients had experienced long term health problems following their transplant and in some, the kidney was no longer working and they had returned to dialysis. Questions related to recipient recovery were asked in both the 3 and 12 month questionnaires.

Main Theme 6 – Regret

Regret was discussed with both pre- and post-operative donors. No post-operative donor regretted their decision to donate, even when the kidney was no longer working:

“I don’t ever regret doing it. I regret that it didn’t work...” (Post-op 15)

When anticipating future regret, donors consistently found it difficult to think of circumstances that would make them regret their decision. Failure of the transplant was not associated with regret as donors felt they had at least made an attempt to help their recipient:

“It wouldn’t be a case of ‘I shouldn’t have bothered’, never” (Pre-op 01)

“I might feel differently about it but it wouldn’t have changed my decision to do it” (Pre-op 02)

“If it didn’t work I don’t think I would regret it because I always say that I am just going to give this my best shot... Even if it doesn’t work I won’t regret it because I know I have tried” (Pre-op 08)
“I am not going to have any regrets for doing this because it feels like the right thing to do... I don’t think I will ever look back at this and say 'you shouldn't have done that'” (Pre-op 05)

Scenarios described by those who had given it some thought included their remaining kidney failing, the recipient not taking care of themselves and a closer member of the family needing a kidney transplant:

“...yes I can think of one situation where I would probably regret it; supposing I had a problem with my remaining kidney to the extent that it failed and I had to go onto dialysis... part of me would say well I wish I had never done this” (Post-op 07)

"Yes, if my kids suddenly needed [one]...” (Post-op 14)

Summary and Conclusions - Regret
No regret and minimal anticipated regret were demonstrated in this sample. In the event of negative outcomes donors anticipated feeling disappointment and regretful towards the outcome, but not for having donated. Questions reflecting anticipated regret pre- and post-operatively and current regret post-operatively were written and asked pre- and post-operatively.

Main Theme 7 – Life after the Transplant (Post-operative Donors only)

Donor-Recipient Relationship
Post-operative donors commonly did not think about the effect of donation on their relationship with their recipient pre-operatively and as a result had not expected it to change. Those whose relationships with their recipient had changed all considered it to have changed for the better with more emotional closeness:

“I don't think I anticipated any different feelings... I think it's closer, definitely, yes.” (Post-op 05)

“It is really weird that all of a sudden you have got that really strong bond” (Post-op 06)

Expectations of the Process
Not all donors’ hopes were translated into expectations following transplantation. For some, not setting any particular expectations was deliberate as they anticipated that they would be disappointed had these expectations not been met. Simply the kidney working was sufficient:
"I just wanted it to work really because I realised it could not work and I think I would have been pretty gutted if I had gone through it all and it had failed...” (Post-op 01)

"I never had any expectations because I think if I had said ‘right it’s going to last 25 years’ ... and it didn’t, I would be disappointed...” (Post-op 02)

These same donors approached their recipient’s health a day at a time, accepting that things could change or deteriorate at short notice. Similarly, donors had also realised over time that transplantation was no ‘quick fix’ and that renal disease would always play a part in theirs and their recipient’s lives. This was not something identified in the pre-operative sample:

“I mean the whole episode just goes from one stage to another, it’s never really over is it? At the end of the day he has still got an organ inside him that isn’t part of his body so I realise he is never going to be completely back to normal... I realised fairly early on, it’s never going to go away... we have accepted that now...” (Post-op 01)

"...you quickly learn in this game, for want of a better word, [it’s] day by day... ‘great we’ve clocked up another day, great... great another day...” (Post-op 02)

The main expectations that were unmet were related to the amount of time the kidney was expected to last. Those who had donated more recently were still below the expected life-expectancy of the kidney and as it had lasted thus far, there was an expectation that it would last for the average amount of time. Where recipients had previously had a transplant and it had been successful, there was an expectation that the new kidney would last a similar amount of time as the last one:

"...one has to be a bit careful with expectations, but I feel that given the 23 years the last one lasted and with better drugs... it might well be sufficient to last her through to the end of her life” (Post-op 07)

For many donors, their expectations had been met or exceeded, which in turn had led to feelings of satisfaction. Recipients had been able to enjoy a better quality of life due to the improvements in their health and the subsequent implications this had on the psychosocial aspects of their lives:

"...yes I think they have... his health has come back, my mother is a lot happier... we fixed a problem, albeit not necessarily forever but we fixed it for what, touch wood, will be a long long time... He’s had a kidney and he’s got better...” (Post-op 04)

"...it’s really sort of exceeded our expectations really...” (Post-op 07)
“I look at where we are now and what it was like in those first few years to think we wouldn’t have imagined this” (Post-op 12)

“...he can now eat lots of things he couldn't eat before... we just had a lovely holiday abroad... it has made a lot of difference” (Post-op 05)

Although donors acknowledged their recipient’s poor health pre-operatively, some felt post-operatively that they had not fully appreciated how unwell their recipient had been:

“... she is back to leading a full life... I didn’t realise how bad she looked until afterwards” (Post-op 14)

**Expectations of the Recipient**

Not all donors had expectations of their recipient. The transplanted kidney was considered to now belong to the recipient and donors felt it was up the recipient to do as they pleased. Some health behaviour expectations were discussed within this context but donors fell short of saying they would impose these behaviours onto their recipient or feel responsible if their recipient’s behaviour had implications on the longevity of the transplant:

“...well that kidney is now his, it's part of his body and it's up to him what he does with it... I mean I suppose the same with anybody generally you would prefer they didn't drink themselves to death or whatever but that's his decision... I wouldn't feel that I'd wasted my time doing it because I would have done what I could... if chooses not to look after it then that's his problem if you like” (Post-op 03)

Expectations of the recipient that were voiced included positive health behaviours, such as taking the appropriate medications, and wanting the recipient to enjoy the new life that a transplant enabled them to have. Some of these had not been met. Parental donors were more involved in instilling good health behaviours in their recipients than non-parental donors. These expectations were similar to those voiced by pre-operative donors [See Main theme 3 – Hopes and Benefits]:

“The thing that we tried that we always tried to drum into him was that you have got to take the correct medication at the correct time...” (Post-op 02)

“I don't want them sitting in an armchair sort of wasting my kidney away. I would rather he did go out and do something with it which is what they are doing” (Post-op 04)

“I do nag her a lot about taking her tablets... I think if she don't take them something might happen...” (Post-op 06)

“I wish, in terms of life in general, for him to do more with his life than he has” (Post-op 08)
Less commonly, donors were awaiting a 'thank you' or acknowledgement from their recipient:

“...the thing I am missing most is a big thank you but [recipient] wouldn’t think of it and I know he is grateful for what I have done... I have not done it to get a thank you, but still [a] word of praise and thank you [would be nice]” (Post-op 09)

**Summary and Conclusions - Life after the Transplant**

Donors who had thought about their relationship with their recipient commonly saw themselves as being emotionally closer after the transplant. This was not something envisaged in the pre-operative donor group, as these donors already saw themselves as being emotionally close. Donors did not disclose many expectations of their recipient but rather had high hopes for the transplant process. However, by their very nature, some of the expectations of the transplant process could only be met through the actions of the recipient. Therefore the donors’ hopes for the transplant process may actually be expectations of the recipient without being considered as such. Many post-operative donors’ expectations had been met, such as an improvement in the recipient’s overall health and quality of life. Expectations of how long the kidney would last were varied, but many were focussed on the length of time they had been told by the transplant team (i.e. 15-20 years).

In addition to the questions to be written about donor expectations [See Main Theme 3 – Hopes and Benefits] questions were written to enquire about a change in relationship at 3 and 12 months, both between the donor and their recipient but also the donor and their immediate social network.

**Main Theme 8 – Donation as a life event**

*Changes in self*

Most commonly, pre-operative donors did not anticipate feeling differently about themselves post-operatively:

“No I can’t really see why to be honest. No I don’t think so” (Pre-op 05)

Some anticipated positive emotions such as pride and satisfaction:

“I think it’s bound to have a positive effect on you… I think it would give you the reassurance that you have done a good thing and you have given someone else a better chance at life” (Pre-op 04)
“I think, seeing [recipient] do the things he wants to do, will always be a good feeling…” (Pre-op 02)

Donation had prompted some to re-evaluate their own health and life in general:

“I think I will probably take a little bit more care of myself… I have started taking a little bit more care of myself [in the lead up to the operation] and I think I will continue that. I appreciate life a lot more now because I’ve realised how precious it is… you just take it for granted and you abuse your body and drink and smoke and eat crap and don’t exercise. But you think when you lose your health… you can’t bring it back so… it has made me appreciate myself a lot more, my life a lot more” (Pre-op 08)

Post-operative donors varied in whether they thought they had changed, both with regard to their character and the life they now led. Donation provided a psychological boost at times of difficulty:

“No I don’t see myself as any different at all, except I have only got one kidney” (Post-op 13)

“… sometimes in life I get depressed and I do remember sometimes thinking ‘well you know I did that and that was quite a big thing’ so when other things have cropped up… I have occasionally thought well ‘I did that [donate] and I got through that without any major problems so I can do this’… it has helped me be a bit more confident” (Post-op 03)

“I’ve got a bit more emotional… I’ve softened up a little bit in a way but in quite a sort of a positive way… I do have a little bit more empathy than I did before… I think it makes you grow up a little bit…” (Post-op 04)

Donors felt very positive about donation and the positive impact it had had on their recipient. A recurring theme was a sense of pride in having overcome fears or having done something good for someone else. Some donors felt privileged to have had the opportunity to donate:

“I felt really proud of myself… when I am with [recipient] sometimes I think about it. I just look at him now and I am just so happy he is still there really…” (Post-op 01)

“I am very pleased that I have done it for my father and actually in hindsight I am very happy that it was the right thing to do… it’s a bit of a privilege really… it will be something I will always look back on with a huge amount of kind of fondness…” (Post-op 04)

 “[I feel] quite proud really, quite proud I think to have been able to do that. I mean, I felt I was lucky to be able to do it. I was fortunate… quite privileged…” (Post-op 05)

“I am proud of myself that I have done it… that I had the courage I suppose to go through with it” (Post-op 06)
”[I have an] increased feeling of self-worth... [you] feel good about yourself... increase in pride but I would not use the word brave... [there is a] spirit of generosity...” (Post-op 08)

Many donors had placed their donation to the back of their minds, reminded only very occasionally by the recipient, the anniversary or by their scar. Others were more vocal about their donation and liked to drop it into conversation with others. Some became embarrassed when friends or relatives brought their donation up in conversation:

”I do feel very good about what I have done and you know I sometimes, it’s a bit like name dropping... my kids even go ‘oh here we go’ [when] I seem to slip in that I donated a kidney” (Post-op 14)

”I mean I would get a bit embarrassed when people [bring it up]... I think ‘leave it alone, it’s enough already’... embarrassed is maybe the wrong word. I just don’t think about it, it’s done now you know over and done with” (Post-op 13)

Failure of the transplant kidney in the short term was associated with guilt and sadness which undermined the positive emotions experienced:

”I think the worst [thing] for me in terms of life afterwards is living with the fact that it hasn’t worked... I felt initially quite happy... I don’t feel so proud of myself about the fact that it hasn’t worked” (Post-op 15)

The views of others
Where donors had received praise from others, many had disagreed with what had been said:

”I’ve had a few people tell me you are very brave with what you are doing; it didn’t even cross my mind about being brave...” (Pre-op 07)

”I don’t think I am a better person or special person for doing this... it’s something that has to be done to actually facilitate life rather than me being a hero... it’s a bit like going into labour really... It’s a part of looking after him really, part of being his mother” (Pre-op 03)

”[My Dad said] ‘I’m really proud of you, it took a lot of guts to do it’... It made me feel really good obviously but you got the impression that some people thought you had done a really brave thing but that is not the way I saw it really...” (Post-op 01)

Some believed others saw them differently after their donation:

”I’m this brave person now. It’s weird...” (Post-op 05)
“I think they [will] definitely have a lot more respect for [me] without a doubt and [my] estimation would have gone up in their book...” (Post-op 11)

“He [Father-in-law] thinks I’m a bit of a martyr” (Post-op 12)

Donors were generally ambivalent about receiving praise from their families; it was nice to hear but was not a necessity to make them feel good or positive about being a donor:

“...it’s always nice to praised isn’t it but it’s not like I would have stopped talking to them if they hadn’t have said it” (Post-op 03)

“[Receiving praise from others] didn’t make any difference. Really it didn’t” (Post-op 13)

Praise had been less than expected for some. Where praise had been lacking from family members, praise from the medical and surgical ward team provided a psychological boost:

“In some ways I have been a little bit surprised at how little people have said” (Post-op 07)

“I suppose deep down you are quite pleased when somebody says you know [you have done a good thing]. I remember... the doctors when they came round... they always made a point of saying ‘you done a brave thing, well done’ and I thought that was really nice... [It made me feel] really good... I felt proud of myself which is not something that I do easily.” (Post-op 09)

There was considerable variation in whether donors felt donation was something anyone would do in their circumstances. Many had received remarks from their friends and family that had surprised them:

“Anyone whose son had gone through what my son went through would willingly have done the same. I don’t feel that I did anything extraordinary... I can’t believe that any parent wouldn’t do the same...” (Post-op 01)

“...my friends almost fell into two camps of absolutely would have done the same to no I wouldn’t have done it... which surprised me a little bit as well...” (Post-op 04)

“I know it’s not what everybody would do, but in my mind it’s what I would do” (Post-op 03)

Donation as a life event

Donation was viewed as being quite different to anything else in life, many claiming that it would be or had been the best thing they had ever done in their lives to date:

“Well it will obviously be the best thing that I have done” (Pre-op 06)
"It is quite different... I helped a granny across the road once but it's not quite the same thing, I didn't give her my kidney" (Pre-op 04)

"Well it's in a completely different league really... I have done a lot of things but to save someone from a life of dialysis it is pretty well top of the list isn't it? I don't think you get as much feeling of reward from anything else really. I don't think I can think of anything else that would compare to that" (Post-op 01)

"[It's] separate, different, on its own out there. I don't think there is anything else to compare to it to be absolutely honest" (Post-op 02)

Not all donors saw donation as an achievement in life. Those who did were most commonly women who felt that they had not achieved much else in their lives and that their donation had somehow made up for this to some extent:

"I think it will be my biggest achievement..." (Pre-op 08)

"When you have led a more mundane life, not been a high flyer... you feel you have actually achieved something, contributed something really worthwhile..." (Post-op 05)

"I know it sounds a bit sad but I don't feel I achieved an awful lot. I mean I've got 4 children, but I think you know I never kind of stayed on at school, done the A levels went to Uni or anything like that and I'm thinking oh I've done something that's a bit different. Not everybody can say they've done that and I think what was really really nice..." (Post-op 14)

**Summary and Conclusions - Donation as a life event**

Pre-operative donors did not envisage a change in how they would see themselves or how others would see them post-operatively. Amongst the post-operative group changes had occurred, both in terms of their characteristics or personality and in their behaviour. Donation provided a boost in confidence for some donors, which in turn helped them in other areas of their lives. Emotions associated with a favourable recipient outcome were positive, whereas poor recipient outcomes (such as graft loss) were not only associated with negative feelings towards the outcome but also the donation itself. This finding suggested that although donation in itself may be perceived to be a positive act, a negative outcome for the recipient counteracts the positive impact. One must consider this within the context of donor held expectations of their recipient (See Main Theme 7 – Life after the Transplant). On reflection, donors viewed their kidney as now belonging to the recipient and subsequently it was up to them to behave as they wished. Bearing in mind the negative effects felt by a donor whose kidney was lost due to no fault of the recipient, one has to wonder whether recipient neglect or non-compliance would have the little effect donors anticipated.
Many donors had received praise from those around them which was considered a good thing, but not a prerequisite to feeling positive about donating. This suggests that the views of the donor towards their donation are not influenced by the views of others. Some donors felt an enormous sense of pride towards their donation and it was seen as being quite different to anything donors had done or achieved in their lives; separate, in a different league and “on its own”. Those who were more likely to see their donation as an achievement were women who felt they had not achieved much else in their lives.

The potential change in donor attitudes towards themselves and their donation are largely unforeseen. This reiterates the importance of measuring psychological factors such as satisfaction with life, wellbeing and self-esteem at more than one time point. All validated questionnaires were asked on three occasions, except for personality which was only asked pre-operatively. From this theme, questions were written to reflect the donors' feelings towards their donation; whether their feelings about donating were dependent on their recipient's outcome, how they felt about being a donor and how it ranked in relation to other things they had done in their lives. Donors were also asked about how much praise they received for being a donor and whether this was important to them. Specific questions related to the impact of donation on self-esteem and the donor's approach to life post-operatively were also written.

Discussion
As discussed in chapter two, there are a number of qualitative studies that have been conducted within the field of living kidney donation. The majority focus on the decision making process and donors' experiences before and after donation. This is the first study which has been conducted with the specific aim of identifying the key psychosocial issues affecting living kidney donors both before and after donation and the first to attempt to identify which factors may impact psychosocial outcomes after donor surgery. As a result of adopting this new approach to living kidney donation, new themes and topics were extracted from the living kidney donation experience and a number of potential predictors of both positive and negative psychosocial outcome were identified.

The decision making process behind living kidney donation was strikingly similar to other living donor studies, and included identical quotes such as the decision being “easy” (Gill and Lowes, 2008, Sanner, 2005, Walsh, 2004, McGrath et al., 2012), a “no
brainer” (Smith et al., 2011) and a natural extension of parental responsibility to a child (Franklin and Crombie, 2003). The decision to become a living donor was most commonly made instantly with little information, with little thought and without consideration of the risks involved (Andersen et al., 2005, Brown et al., 2008, Gill and Lowes, 2008, McGrath et al., 2012). The decision to donate was firm, was not influenced by the donor’s fears or the negativity of others and was rationalised after the decision had already been made (Fellner and Marshall, 1968, Walsh, 2004, Higgerson and Bulechek, 1982, Eggeling, 2000, Yeh et al., 2012). Donors most commonly offered to donate their kidney rather than being asked (Gill and Lowes, 2008, Eggeling, 2000, Smith et al., 2011, McGrath et al., 2012). Reference was also made to the role that some donors played in their recipients’ life and the expectations that came with that role. For example, parents were socially and culturally expected to donate (both by their recipient and others) and as a result, the conversation about whether or not one of the recipient’s parents would donate a kidney never took place (Andersen et al., 2005, Crombie and Franklin, 2006). The issue of choice has also been discussed previously, with some donors remarking how they felt that they did not have a choice, despite being told by the transplant team that they did (Crombie and Franklin, 2006).

These findings add further support to studies which suggest that informed consent within the context of living donation is a myth (Fellner and Marshall, 1968, Alnaes, 2012, Yeh et al., 2012). This is because the majority of people make their decision instantly, and also the lack of options available to someone who wishes to make a rational decision about whether to donate or not. More rational decision making involves the weighing up of different options, which in this context includes deciding whether to donate when perhaps someone may not wish to, versus watching someone they love deteriorate and possibly die as a result of not receiving a transplant. It is easy to see how in this situation, an individual may not feel that they have a choice (Crombie and Franklin, 2006).

The donors in this study also shared the same motivations as donors in other studies. They sought normality for their recipient, wanted to save their life or improve their quality of life by removing the physical constraints of renal failure and its treatment (i.e. dialysis) (Andersen et al., 2005, Haljamäe et al., 2003, Higgerson and Bulechek, 1982, Gill, 2012, McGrath et al., 2012). The pre-operative donors in this study did not anticipate seeing themselves differently or being seen as different by others after donation. Post-operative donors, who too had not envisaged a change in themselves
pre-operatively, did see themselves differently once they had reflected on their experience over the months and years that had followed. This finding is similar to that demonstrated in two studies by Andersen and colleagues who interviewed the same twelve donors one week and one year after donation (Andersen et al., 2005, Andersen et al., 2007). At one year post-donation donors had experienced more benefits than anticipated, including pride, increased self-esteem and personal growth. The donors in this study similarly felt proud, gained confidence and self-esteem, and these findings are additionally documented elsewhere (Brown et al., 2008, Fellner and Marshall, 1968, Franklin and Crombie, 2003). They additionally remarked that donation was one of the best things they had done and was also something that was quite different to anything else they done previously in their lives or had previously achieved (Fellner and Marshall, 1968, Franklin and Crombie, 2003). Other people in their family and social network had also treated with them with more respect and viewed them as a hero or as a martyr. Some had additionally become closer to their recipient, which again was something that had not been anticipated (Fellner and Marshall, 1968, Higgerson and Bulechek, 1982).

Similarly to the quantitative literature, many qualitative studies that have considered outcomes in living kidney donors after donation have focussed on harm. This includes the negative psychosocial impact of living donation itself and the impact of graft loss or recipient death. Negative outcomes following living donation in this study sample included recurrence of obsessive compulsive disorder symptoms, emotional fragility and feelings of vulnerability; the latter of which have been documented elsewhere (Brown et al., 2008).

The post-operative recovery period was commonly different to how donors had anticipated it, with some having a much better experience than was expected and others commenting that the pain and physical impact of surgery was considerably worse than expected. It was common for those expecting high amounts of pain to experience less pain, and vice versa. There are a number of psychological theories and models related to patient expectations of pain and recovery after surgery (Wallace, 1985), some of which are conflicting, and it is difficult to determine which theory the findings from this study are most in keeping with. This is principally because the data provided by this study is qualitative and no objective information was available regarding the clinical pain management strategy or the donors’ pre-operative psychological state prior to surgery, which is also known to have an impact on pain and symptom perception (Johnston, 1981).
Other qualitative studies have identified experiences that did not emerge from this study. These include feelings of loss and grief (Andersen et al., 2007, Kemph, 1967, Kemph, 1970, Higgerson and Bulechek, 1982), abandonment and neglect by the transplant team (Sanner, 2005, Gill, 2012), anxiety towards their own or the recipient’s health (Andersen et al., 2007, Heck et al., 2004, Haruki, 1989, Karrfelt et al., 2000), and low mood and depression (Fellner and Marshall, 1968, Higgerson and Bulechek, 1982, David, 1974). Negative social outcomes reported in other studies were similar to those extracted from this study and included relationship difficulties, employment issues and financial hardship (Greif-Higer et al., 2008, Karrfelt et al., 2000).

No donors in this study had experienced recipient death; however two had experienced graft loss. One individual was very religious and remained philosophical about their feelings towards what had happened, stating that it was God’s will. The other had clearly been profoundly affected by the loss of the kidney and experienced ongoing guilt and sadness, which in turn had undermined the positive emotions they had initially experienced. The experience of graft and recipient loss is well documented in the qualitative literature. It is associated with inferior psychosocial outcomes, including mental distress, including feelings of sorrow and emptiness, rejection, depression, guilt, fear for the recipient (Andersen et al., 2007, Haljamäe et al., 2003, David, 1974). Donors experiencing graft or recipient loss took longer to recover in some cases, principally due to low mood and physical fatigue and weakness (Andersen et al., 2007). One study has described two cases of donor suicide in the event of graft failure and recipient death (Weizer et al., 1990). Regret was not experienced by any of the donors in this study, even in the event of graft loss, and this is in keeping with other studies (Andersen et al., 2007, Brown et al., 2008, Higgerson and Bulechek, 1982, Eggeling, 2000, Karrfelt et al., 2000).

As mentioned above, this is the first study that has been conducted with a view to identifying what factors may be associated with donor psychosocial outcome. The studies discussed above have addressed the issue of graft and recipient outcome having a negative impact on donor outcomes, however there are no indicators for who has a positive experience, or who has a negative experience in the absence of a poor recipient outcome. Due to the approach taken by this study, a number of new concepts have emerged out of the data, which have not previously been discussed.

Pre-operatively, donors varied considerably in how much their recipient illness had affected them. Donors whose recipients had been unwell for a long time, and those
providing a caregiver role, appeared to be more affected than those whose recipients had experienced a short illness, or where the donor did not provide a caregiver role. Donors described in detail the negative physical, social and psychological impact that renal failure had on their recipient. The impact of renal failure on the donors mirrored those experienced by their recipients. For example, they were similarly restricted by the weekly dialysis schedule, their recipient’s dietary requirements and the unfeasibility of holidays. Consequently donors perceived the personal benefits of transplantation to be indirect and lie primarily within the recipient’s outcome rather than in the act of donation itself. This was due to the widespread physical, psychological and social benefits that were associated with the recipient being well and was especially the case in spousal donors, where restoring life as a couple was important. Similar issues within spousal donation have been discussed in one other study (Gill and Lowes, 2008).

Another new finding from this study was that being asked to donate triggered an immediate response to say yes. Responses were associated with feelings of entrapment and heightened stress and anxiety. The size of the potential donor pool was also an important factor, with those who were the only potential donor also experiencing more stress and anxiety. These concepts are closely related to the issues surrounding lack of choice and informed consent which are discussed above. The availability of alternative donors may be associated with less stress and anxiety primarily because alternative donors may be pursued in the event of a medical problem, but secondarily they also provide the donor with the opportunity to withdraw from the donation process without necessarily condemning their potential recipient to death or a poor quality of life.

Prior to any discussions related to living donation many donors had experienced episodes where their recipient had deteriorated very rapidly and had ended up in intensive care. These episodes were very frightening and traumatic for all of them. They were able to vividly recall fearing for the recipient’s life and these fears resurfaced at the time that living kidney donation was first discussed. For donors with these memories, living donation was a life-saving procedure rather than one which would improve the quality of their recipient’s life, despite the fact that their recipient's renal failure was no longer seen as being life threatening. While the study was retrospective, the vividness with which these memories and the associated emotions was extensive and consistent, regardless of the length of time since the event.
With regard to anticipating benefits after donation, a new issue that emerged from the data was the sense of guilt and selfishness that some donors felt when acknowledging a benefit to themselves, which might explain the previous lack of available data on donor benefit after living donation. This study demonstrated that donors wish to be perceived by the transplant community to be giving their gift unconditionally and feared that an acknowledgement of benefit to themselves may be perceived as being an ulterior or unacceptable motive.

This study has further reiterated that living kidney donation has a complex, profound and multi-faceted impact on the lives of donors (Tong et al., 2012a). Living kidney donors are a diverse group of individuals with varied experiences, who are affected differently by their recipient’s illness. They are therefore likely to approach living donation in very different ways. This study was conducted prior to a quantitative study in order to develop a more in-depth understanding and appreciation of the topic, prior to generating hypotheses and deciding on what factors ought to be measured and how. The results highlighted a need to measure a range of psychosocial factors before and after donation. These include wellbeing, mood, stress, anxiety, self-esteem, life satisfaction, optimism, social support and social comparison. All of these factors were subsequently measured in the quantitative study through the use of validated measures. Demographic data, such as age, gender and the donors’ experiences within the healthcare system were also deemed important, with special attention paid to mental health diagnoses.

Factors specific to living kidney donation were collected by writing new questions. These included details of the recipient’s circumstances (i.e. dialysis history, previous transplant history, and whether they lived with or were cared for by the donor) and the donor’s decision making process, such as whether the decision to donate was instant, whether alternative donors were available, whether they offered to donate and the level of anxiety related to the donation process. Donors were also asked how easy it would be to withdraw from the process should they wish to and how easy or difficult it would be to communicate these feelings to their recipient, friends, family and the living donor team. Life after the transplant was also considered, principally reflecting the donors’ pre-operative expectations and whether these were met post-operatively. Questions addressed regret, anticipated regret, self-esteem and the views of others.

The strengths in this study lie in the both the size of the sample and the inclusion of both pre- and post-operative donors. Additionally, the breadth of questions also
allowed for discussion of the entire living donation process. The limitations of this study lie in its cross-sectional approach. A longitudinal study would have allowed donors to be interviewed pre- and post-operatively in order to demonstrate change in attitudes or beliefs over time. Some donors were likely to be affected by recall bias, especially those who donated many years ago. That said, many donors remarked that their donation was such a significant event in their life that they could recall many of the memories and emotions they had felt during their donation experience. In addition, the memories of the pre-operative period recalled by post-operative donors were very similar to those currently being experienced by the pre-operative donor group. This added reassurance that the experiences recalled by those who had donated many years previously were accurate.

**Summary**

This qualitative study provided a valuable insight into the factors affecting living kidney donors. The outcomes uphold the findings of other qualitative studies into living kidney donation that have described the topic as complex and multifaceted. This study has resulted in a number of new findings which focus more specifically on predicting psychosocial outcomes. The results have generated a number of hypotheses, which have guided the structure of the questionnaire used in the quantitative study. An in-depth discussion of these are the subject of the following chapter.

**Reflexive Practice**

Reflexivity or reflexive practice is an evaluative process which is designed to increase the integrity and trustworthiness of qualitative research by analysing and evaluating how the researcher's own role within the study may influence the data collection and analysis.

As noted in the methods section, prior to this study being conducted I had worked as a surgical trainee with six months clinical experience in transplantation and living donation. My role had predominantly been to take care of donors on the ward both before and after donation and to assist a consultant surgeon during the donor operation. I had no experience in assessing whether potential donors would be suitable for transplantation and therefore I was naïve to what a donor would have gone through in order to be allowed to donate. Although I had an appreciation of the medical tests involved to assess physical suitability for donation, I did not have any experience of having spoken to donors in any detail about their experience and as a
result, I had a very limited understanding of the psychosocial issues pertinent to living donation.

This allowed me to approach the interviews with an open mind and with very few, if any, preconceptions about what the interviewees would tell me. Consequently, I feel that I have benefitted considerably from having conducted this study, not only in terms of how the thesis has evolved, but for my future clinical practice. My prior minimal involvement with a high volume of donors meant that I had inadvertently dehumanised them and saw them as “just another donor” rather than an individual person who was likely to have endured a number of challenges prior to setting foot on the ward on the morning of their operation. I now have a much better appreciation of how complex and multi-faceted living donation really is.
Chapter 4  
Longitudinal Study of Psychosocial Outcomes – Methodology and Questionnaire Development

Introduction
A review of the literature outlined in chapter two concluded that the majority of living kidney donors had a very positive experience of donation with very few suffering post-operative psychosocial complications. However, the methodological issues identified with many of these studies made the findings questionable, inaccurate and unreliable. The different methodologies used within the literature also meant that there were broad inconsistencies between different studies, with no explanation as to why some donors had experienced negative outcomes. There was a noticeable incongruence between the qualitative and quantitative literature. Whereas the qualitative literature identified and described living donation as being a complex and multidimensional topic, the quantitative literature predominantly consisted of very simple studies that commonly used generic questionnaires at a single post-operative time point. Detailed quantitative studies focussing on donor benefit were lacking and no quantitative study had attempted to measure a comprehensive range of psychosocial factors. The chapter concluded by highlighting the need to conduct a more comprehensive quantitative study in order to answer some key questions about living kidney donation that remain unanswered.

A longitudinal prospective study was conducted as part of this thesis and this chapter outlines its methodology. The main themes identified from the qualitative study (chapter 3) are revisited and the hypotheses are outlined. The validated measures selected for inclusion in the study questionnaire are described, as well as the justification for writing new donation and transplant-specific questions, where appropriate. A detailed description of how the new questions were written and validated is provided alongside the results of the relevant statistical tests. Finally the recruitment strategy for the study is outlined with a brief description of the perioperative living donation period. The results and conclusions of the study are outlined and discussed in chapter 5.

Rationale for the study design
Although the number of prospective studies conducted within the field of living kidney donation are limited in number, a large proportion (56%) demonstrate an increase in post-operative psychopathology after donation has taken place (Varma et al., 1992, Yoo
et al., 1996, Taghavi et al., 2001, Smith et al., 2004, Bergman et al., 2005, Lumsdaine et al., 2005, Minz et al., 2005, Virzi et al., 2007, Shrestha et al., 2008, Chien et al., 2010, Lopes et al., 2011, Joshi et al., 2013, Kroencke et al., 2012, Bahler and Sundaram, 2013). A prospective longitudinal study was selected in order to investigate these findings further and to determine not only whether psychosocial factors change over time but if so, over what trajectory. A self-completion questionnaire was selected in order to minimise research visits to the hospital following donation. This was important for the donor population due to the multiple hospital appointments they would have already attended as part of their workup and even more important for those donors living outside the hospital catchment area or overseas.

A single pre-operative time point and two post-operative time points were used to assess the difference between pre- and post-operative scores and to assess the impact of living donation across both the short and long term recovery period. The short term recovery period selected was 3 months as this marks the end of the recommended convalescence period as outlined in the UK national guidelines (British Transplantation Society, 2011) and is typically when donors return to work and normal activities. The long term recovery period selected was 12 months because this marks the start of the annual review process. At this point, donors attend the hospital or their General Practitioner for a medical review, blood pressure check, urine dipstick test and blood tests, including an assessment of kidney function. If any issues are identified at this appointment then the donor is referred accordingly.

The qualitative study highlighted the need to measure a range of psychosocial factors. These are listed in Table 4.1 alongside the validated outcome measure that was chosen for this study. Details of the different validated measures chosen are provided later in this chapter [Questionnaire design – validated measures].
### Table 4.1 – Psychosocial factors to measure and the validated measure selected

<table>
<thead>
<tr>
<th>Psychosocial factor to measure</th>
<th>Validated measure selected</th>
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<tbody>
<tr>
<td>Wellbeing</td>
<td>Office of National Statistics Wellbeing questions</td>
</tr>
<tr>
<td>Distress</td>
<td>General Health Questionnaire 12</td>
</tr>
<tr>
<td>Depression</td>
<td>Patient Health Questionnaire 2 (PHQ-2)</td>
</tr>
<tr>
<td>Stress</td>
<td>4 item Perceived Stress Scale (PSS)</td>
</tr>
<tr>
<td>Health-Related Quality of Life</td>
<td>Short Form 12 (Physical components only)</td>
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<tr>
<td>Life Satisfaction</td>
<td>Satisfaction with life scale (SWLS)</td>
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<tr>
<td>Self-Esteem</td>
<td>Rosenberg</td>
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<tr>
<td>Personality*</td>
<td>10 item personality inventory (TIPI)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>6-item State-Trait Anxiety Inventory (STAI-short)</td>
</tr>
<tr>
<td>Social support</td>
<td>Multidimensional Scale of Perceived Social Support</td>
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<td>Optimism</td>
<td>Life Orientation Test - Revised</td>
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<tr>
<td>Social comparison</td>
<td>Social comparison scale</td>
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</tbody>
</table>

*measured pre-operatively only

**Study hypotheses**

Based on the findings of the qualitative study, the three main study hypotheses are:

**Hypothesis 1**

That there are a number of donor and transplant-related factors that will be associated with poorer than average psychosocial questionnaire scores pre-operatively. These include the following:

1.1 **Parental Donors**: I hypothesize that those donating to one of their children will be more stressed, anxious, distressed and have lower mood, wellbeing and life-satisfaction.

1.2 **Primary caregivers**: I hypothesize that those donors who are the primary caregiver to their recipient will also be more stressed, anxious, distressed and have lower mood, wellbeing and life-satisfaction.

1.3 **Donors whose recipients were on dialysis**: I hypothesize that these donors will be more distressed.

1.4 **Donors who were asked to donate**: I hypothesize that these donors will demonstrate increased pre-operative stress, anxiety and distress.

1.5 **Donors who were the only available donor for their recipient**: I hypothesize that these donors will also demonstrate increased pre-operative stress, anxiety and distress.
Hypothesis 2
That, on average, scores across a number of measures will show an improvement after donation whilst some will remain unaffected. More specifically:

2.1 I hypothesize that scores for the following psychosocial factors will increase after donation: wellbeing, life satisfaction, self-esteem and social comparison.
2.2 I hypothesize that scores for the following psychosocial factors will decrease after donation: distress, depression, stress and anxiety.
2.3 I hypothesize that the following scores will remain the same 12 months after donation: physical health-related quality of life, social support and optimism. Physical health-related quality of life scores will decrease at 3 months but will return to normal by 12 months.

Hypothesis 3
That the psychosocial wellbeing of a subset of donors will improve after donation and a subset will decline. More specifically:

3.1 I hypothesize that the following donors will demonstrate an improvement 12 months after donation:
  3.1.1 Primary caregivers
  3.1.2 Parents

3.2 I hypothesize that the following donors will demonstrate a decline 12 months after donation:
  3.2.1. Donors who experienced post-operative complications
  3.2.2. Donors whose recipients had died or lost their kidney within the study period
  3.2.3. Donors whose recipients experienced post-operative complications
  3.2.4. Donors whose relationships with their recipient or others around them had deteriorated since the donation took place

Questionnaire design
As mentioned above, the study questionnaire included a range of validated psychosocial outcome measures and new questions related specifically to transplantation and the living donation process. These will now be discussed in detail. Full versions of the pre-operative and post-operative questionnaires as completed by the participants are available in appendices 3 and 4.
Validated measures

The validated measures selected are described below. These were the first questions completed by participants and are listed in the order in which they appear within the questionnaire. They were selected based on their psychometric properties. Validated abbreviated versions of popular measures were used whenever possible to reduce responder burden.

Wellbeing - Office of National Statistics (ONS) Personal Wellbeing questions (Dolan et al., 2011)

The ONS personal wellbeing questions were developed as part of the UK Measuring National Well-being Programme. The ONS sought advice from experts working within the field of subjective well-being and consulted with specialists on the National Statistician’s Measuring National Well-being Advisory Forum and Technical Advisory Group before devising 4 items which capture data on life satisfaction, happiness, anxiety and worthwhileness (Dolan et al., 2011). Each item is answered on an 11 point scale, ranging from 0 to 10. Items 1, 2 and 4 are positively scored and item 3 (worry) is reverse scored. These questions were placed at the start of the questionnaire as advised by the ONS (Office of National Statistics, 2013). Higher scores indicate higher personal wellbeing. Scores obtained from the 2012-2013 Annual Population Survey conducted by the Office of National Statistics provided an average score of 29.4 for the UK population (n=165,000) (Office of National Statistics, 2012).

Distress - General Health Questionnaire 12 (Goldberg and Williams, 1988)

The 12-item General Health Questionnaire (GHQ-12) is an abbreviated version of the 60 item original. It is a self-administered screening instrument designed to detect current diagnosable psychiatric disorders (McDowell, 2006) and in this study was included to measure distress. Each question has 4 possible answers which can either be coded as per a Likert scale (0-3), or alternatively as a two point score where the intensity is ignored and a problem is recorded as being either present or absent (0 or 1). Likert scoring was used for this study, which subsequently meant that donors could score between 0-36, with higher scores indicating more distress. No items are reverse scored. The authors state that scores between 11 and 12 are average, with those scoring above 15 demonstrating evidence of distress and those scoring above 20 demonstrating severe psychological distress.
Depression - Patient Health Questionnaire 2 (Kroenke et al., 2003)
The PHQ-2 is an abbreviated version of the 9 item full version (Kroenke et al., 2001) and is intended to be used as a depression screening tool. It enquires about the frequency of depressed mood and anhedonia over the preceding 2 weeks. In this study it was used to measure depression. Each question has 4 possible answers: 0 = not at all, 1 = several days, 2 = more than half the days and 3 = nearly every day, meaning that donors could score between 0 and 6 in total. A PHQ-2 score of ≥3 has a sensitivity of 83% and a specificity of 92% for major depression.

Stress - 4 item Perceived Stress Scale (PSS) (Cohen et al., 1983)
The 4-item version of the PSS was used to measure the degree to which situations in one’s life over the preceding month are viewed as stressful. Answers are based on a five-point scale: 0 = never, 1 = almost never, 2 = sometimes, 3 = fairly often, 4 = very often. Scores are obtained by summing up all four items, two of which are reverse scored (items 2 and 3). Total scores range from 0-20 with higher scores indicating more perceived stress. No cut-off scores are available for the 4-item PSS, however normative data provided by a large US population study, conducted by the creators of the questionnaire in the same year that the measure was devised, gave an average score of 4.5 (Cohen, 1983).

Health-Related Quality of Life - Short Form 12 (SF-12) (Physical components only) (Ware et al., 1996)
The short-form measures are well established generic measures of health related quality of life and have been used extensively within healthcare and within the living donor population. In order to capture data on the physical aspects of quality of life, the physical component questions of the short-form 12 were included in the questionnaire. The mental component questions were removed as other questionnaires measuring psychological factors were being used throughout the questionnaire and there was a desire to reduce responder burden as much as possible. There are 7 physical component questions in the SF-12, which enquire about a participant’s ability to perform simple day to day activities. These questions were scored 1-3 or 1-5, depending on the question. Total scores ranged from 7-31 with higher scores indicating higher physical health related quality of life.

Life Satisfaction - Satisfaction With Life Scale (SWLS) (Diener et al., 1985)
The SWLS was developed to assess satisfaction with the respondent’s life as a whole, allowing subjects to weight the different domains that may determine life satisfaction.
(such as health or finances) in whichever way they choose. It is for this reason that the SWLS is recommended for use alongside other scales that focus on psychopathology or emotional wellbeing as it “assesses an individuals’ conscious evaluative judgement of his or her life by using the person’s own criteria” (Pavot and Diener, 1993). The SWLS comprises 5 items which are scored on a 7 point Likert scale: 1 = strongly disagree, 2 = disagree, 3 = slightly disagree, 4 = neither agree or disagree, 5 = slightly agree, 6 = agree, 7 = strongly agree. There are no reverse scored answers and the range of scores is therefore 5-35. Higher scores indicate higher life satisfaction. Scores can be interpreted in terms of absolute as well as relative life satisfaction. The midpoint of the scale is 20, indicating that the individual is equally satisfied and dissatisfied. Normative data is available for a range of diverse populations and when amalgamated suggest a score between 23 and 28 to be average (Pavot and Diener, 1993); thereby indicating that most individuals fall within the slightly satisfied (21-25) and satisfied (26-30) range.

Self-Esteem - Rosenberg (Rosenberg, 1965)
This 10-item scale measures global self-worth by measuring both positive and negative feelings towards oneself. Items are scored on a 4 point Likert scale: 3 = strongly agree, 2 = agree, 1 = disagree, 0 = strongly disagree. Items 2, 5, 6, 8 and 9 are reversed. The range of scores is 0-30 with higher scores indicating higher self-esteem. Normative data available from the authors of this measure (taken from a survey of US high school students) suggest a normal range of 15-25, with a score of less than 15 indicating low self-esteem. This is the only validated self-esteem measure that has been used within the living donor population (Simmons and Anderson, 1982).

Personality- 10-item personality inventory (TIPI) (Gosling et al., 2003)
This scale provides a brief assessment of “The Big Five” personality dimensions. It includes ten items, two for each of the personality traits extraversion, agreeableness, conscientiousness, openness and emotional stability. Participants are provided with a pair of analogous personality characteristics and are asked to select an answer based on how much they identify with them. Answers are based on a seven-point scale: 1 = Disagree strongly, 2 = Disagree moderately, 3 = Disagree a little, 4 = Neither agree nor disagree, 5 = Agree a little, 6 = Agree moderately, 7 = Agree strongly. Five items, one for each personality trait, are reverse scored. A sum score for each personality trait was calculated from both questions, with higher scores indicating that the individual identifies more with that particular personality trait.
Anxiety - 6 item State-Trait Anxiety Inventory (STAI-short) (Marteau and Bekker, 1992)

The 6-item STAI is an abbreviated version of the 40 item measure, originally designed to measure the presence and severity of current symptoms of anxiety (Julian, 2011). A 6-item measure was subsequently developed for use in circumstances where the 40-item measure is inappropriate and provides results that are comparable to those obtained from the full form. The 6-item STAI measures state anxiety only; that is a temporary state of anxiety which is related to how the individual is feeling at the time (McDowell, 2006). Each question is answered on a 4-item Likert scale: 1 = not at all, 2 = somewhat, 3 = moderately, 4 = very much. Questions 1, 4 and 5 are reverse scored. The range of scores is 6-24, with higher scores indicating higher state anxiety. Normative scores were not available for this questionnaire.

Social support - Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet et al., 1988)

This 12-item questionnaire measures perceived social support from three sources: family, friends and significant others. Each question is answered on a 7 point Likert scale: 1 = very strongly disagree, 2 = strongly disagree, 3 = mildly disagree, 4 = neutral, 5 = mildly agree, 6 = strongly agree, 7 = very strongly agree. There are no reverse scored items and possible scores range from 12 to 84, with higher scores meaning a higher degree of perceived social support. Normative scores were not available for this questionnaire. The MSPSS has shown high internal reliability (Cronbach's alpha = 0.87, 0.85, and 0.91 respectively for the family, friends and significant others subscales) (Tonsing et al., 2012).

Optimism - Life Orientation Test – Revised (LOT-R) (Scheier et al., 1994)

This 10-item version of the Life Orientation Test was used to measure optimism, or more specifically, a person's expectations regarding the favourability of future outcomes. Answers are based on a five-point scale: 0 = strongly disagree, 1 = disagree, 2 = neutral, 3 = agree and 4 = strongly agree. Four of the items are fillers and are not used in scoring. A final score is obtained by summing up the remaining 6 items, of which 3 are reverse scored (items 3, 7 and 9). Total scores range from 0-24 with higher scores indicating higher optimism. The is no defined cut-off or benchmark for being an optimist or pessimist, however scores between 0 and 13 indicate low optimism, scores between 14 and 18 indicate moderate optimism and scores between 19 and 24 indicate high optimism.
Social comparison - Social comparison scale (Allan and Gilbert, 1995)

This 11-item scale was developed to measure self-perceptions of social rank and relative social standing. It uses a semantic differential methodology and participants are required to make a global comparison of themselves in relation to other people. The questionnaire asks participants to complete the sentence “In relationship to others I generally feel...” by putting a mark on a ten point scale which is anchored at each end with following bipolar constructs: inferior-superior, incompetent-more competent, unlikeable-more likeable, left out-accepted, different-same, untalented-more talented, weaker-stronger, unconfident-more confident, undesirable-more desirable, unattractive-more attractive, an outsider-an insider. The range of possible scores is 11-110, with low scores indicating feelings of inferiority and general low rank self-perceptions. Normative scores were not available for this questionnaire.

New questions

As discussed above and within the qualitative study, a number of donor and transplant-related factors were identified as being potential predictors of outcome. Pre-operative factors included how and how long ago the decision to become a donor was made, whether the participant volunteered and whether any other family or friends were suitable alternatives. The carer status of the donor, their expectations of the process and their concerns and anxieties specific to donation were also important. Post-operative factors included the impact of post-operative complications (both in the donor and the recipient), the meeting of expectations and regret. The living donor literature was revisited, paying specific attention to those studies which had used validated questionnaires specific to donation. Of the 8 studies found, none had used a questionnaire that sufficiently captured the themes identified in the qualitative study (Simmons and Anderson, 1982, Smith et al., 1986, Gouge et al., 1990, Westlie et al., 1993, Corley et al., 2000, Rudow et al., 2005, Stothers et al., 2005, Fisher et al., 2005). The decision was therefore made to write new questions for this study questionnaire, based on the factors identified above.

The first step in the question writing process involved revisiting the eight main themes defined in the qualitative study. Those donor or transplant-related factors that were deemed important were then extrapolated from the qualitative themes and labelled ‘question themes’. Questions were then written using colloquial language so that they would be unambiguous and easily understood by individuals with an average reading age. As in the qualitative study, questions were ordered chronologically to ease information recall and to take the donor through the donation process in a methodical,
logical manner. Answer options were provided in order to make the questionnaire easier to complete. The majority of question responses were provided in a Likert scale format. Likert scales are a well-known and well understood method of survey data collection and were therefore likely to be familiar to the participants. By providing participants with a degree of agreement or disagreement with a particular phrase, Likert scales do not force the participant to provide a concrete yes or no answer, which in turn makes the question easier to answer. By providing a “neither agree nor disagree” type option they also accommodate neutral or undecided feelings. Additionally, for the researcher, Likert responses are easy to code, analyse and interpret.

Once the first draft of the questionnaire had been written it was reviewed and modified by the thesis supervisors and a colleague who had experience with quantitative research (JC – lecturer in health psychology). The questions then underwent validity and reliability testing prior to finalisation. The reliability and validity testing process is described below. The qualitative themes, question themes, final questions and possible answers are provided in Table 4.2, alongside the time points at which they were asked.

**Questionnaire Validation**

It is essential for new questions to undergo validity and reliability testing in order to minimise the possibility of incorrect conclusions being made from the data. Validity refers to how well a test measures what it is intending to measure whereas reliability refers to how well a measure or set of measures produces stable and consistent results. Not all aspects of questionnaire validation and reliability testing were applicable for the donor and transplant-related questions. Both validity and reliability testing methodologies and results are discussed below.

**Validity testing**

There are many different types of validity testing. The terms “face validity” and “content validity” are descriptions of the judgement that a scale looks reasonable (Streiner and Norman, 2008). Face validity testing requires the opinions of experts reviewing and assessing the necessary questions and possible answers to ensure that the questions appear to be assessing the desired qualities. Content validity is a closely related concept and refers to whether or not the measure captures the relevant or important questions related to the subject. Although the new questions written as part of this study were devised following an in-depth qualitative study, both face and
<table>
<thead>
<tr>
<th>Qualitative Theme</th>
<th>Question Theme</th>
<th>Questions written</th>
<th>Possible answers</th>
<th>Time point</th>
</tr>
</thead>
<tbody>
<tr>
<td>Circumstances of Donation</td>
<td>Length of time between first discussion and donation</td>
<td>How long ago did you first consider being a Living Kidney Donor?</td>
<td>Less than 6 months, 6-12 months, 1-5 years, More than 5 years ago</td>
<td>Pre-operative</td>
</tr>
<tr>
<td>Becoming a Living Donor</td>
<td>Severity of illness at the time of decision making</td>
<td>At the time you first agreed or decided to donate, how well or unwell was your recipient?</td>
<td>Extremely unwell, Unwell, Neither well nor unwell, Well, Very well</td>
<td></td>
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<tr>
<td></td>
<td>Instant or moral decision making</td>
<td>How much do you agree or disagree with the following statement – “When Living Donation was first mentioned I knew instantly that I would be prepared to donate”</td>
<td>Strongly agree, Agree, Neither agree nor disagree, Disagree, Strongly disagree</td>
<td></td>
</tr>
<tr>
<td>Offered or was asked to donate</td>
<td></td>
<td>Which of the following statements best describes your donation?</td>
<td>I offered to donate my kidney without being asked by anyone else I was asked to donate by the person I am donating to I was asked to donate by someone else (please state who)</td>
<td></td>
</tr>
<tr>
<td>Number of other donors available</td>
<td></td>
<td>How many other people (EXCLUDING YOURSELF) offered to donate a kidney to your recipient? How many other people (EXCLUDING YOURSELF) went for tests AND were suitable to donate? (i.e. were a match and medically fit enough)</td>
<td>Asked to provide number of people</td>
<td></td>
</tr>
<tr>
<td>Communication between donors and recipients, family, friends and the living donor team</td>
<td></td>
<td>In the event of concerns or doubts about going through with the operation, how easy would it be (or has it been) to discuss these with – Your recipient Your family Your friends The living donor team</td>
<td>Very easy, Easy, Neither easy nor difficult, Difficult, Very difficult</td>
<td></td>
</tr>
<tr>
<td>Qualitative Theme</td>
<td>Question Theme</td>
<td>Questions written</td>
<td>Possible answers</td>
<td>Time point</td>
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<tr>
<td>Desire for the transplant to happen</td>
<td>How much do you agree or disagree with the following statement: “Of all the people involved I was the person pushing most for the Living Donor transplant to happen”</td>
<td>Strongly agree, Agree, Neither agree nor disagree, Disagree, Strongly disagree</td>
<td>Pre-operative</td>
<td></td>
</tr>
<tr>
<td>General attitudes towards donation</td>
<td>How much I benefit from my donation will depend very much on how well my recipient does I think organ donation (in general) is a good thing I feel good about being a kidney donor</td>
<td>Strongly agree, Agree, Neither agree nor disagree, Disagree, Strongly disagree</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Markers of other altruistic behaviour</td>
<td>Do you give blood? Are you on the bone marrow register or have you been a bone marrow donor? Are you on the organ donor register and/or do you hold an organ donor card? Do you volunteer in your free time? Do you regularly give money to charity?</td>
<td>Yes, No, Not anymore, Unsure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hopes and Benefits Life after the Transplant</td>
<td>Expectations of life after transplantation for recipient, self and others</td>
<td>After the transplant my recipient's DAY-TO-DAY life will get better After the transplant my own DAY-TO-DAY life will get better After the transplant the DAY-TO-DAY life of those around me will get better</td>
<td>Strongly Disagree, Disagree, Neither Agree or Disagree, Agree, Strongly Agree</td>
<td>Pre-operative</td>
</tr>
<tr>
<td></td>
<td>Meeting of pre-operative expectations</td>
<td>My recipient’s DAY-TO-DAY life is much better now than before the transplant My own DAY-TO-DAY life is much better now than before the transplant The DAY-TO-DAY lives of other people around me are better now than before the transplant</td>
<td>Strongly Disagree, Disagree, Neither Agree or Disagree, Agree, Strongly Agree, Unable to comment</td>
<td>3 months 12 months</td>
</tr>
<tr>
<td></td>
<td>Donor workup, Risks and Worries</td>
<td>Duration of the living donor workup process</td>
<td>How long did it take for you to donate? (From initial discussion with a transplant co-ordinator to the operation)</td>
<td>Within 6 months, 6-12 months, 12-24 months, More than 24 months</td>
</tr>
<tr>
<td>Qualitative Theme</td>
<td>Question Theme</td>
<td>Questions written</td>
<td>Possible answers</td>
<td>Time point</td>
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</tr>
<tr>
<td>Donor workup, Risks and Worrries</td>
<td>Concerns / anxieties related to donation and how much this occupies the donor’s thoughts</td>
<td>Since you first agreed or decided to donate how often have you thought about it? Since deciding to be a Living Kidney Donor, how often have you thought about: The process you will have to go through? (This can include any part of the donation process, including the pre-operative work up, your operation, your stay in hospital and your recovery afterwards.) Your social circumstances and how these may be affected by donating? (This can include any social issue, such as money, childcare, housing, work etc.) When thinking about your RECIPIENT, how much do you worry about something going wrong or the transplant being unsuccessful?</td>
<td>Never, A few times a month, A few times a week, Every day, I think about it constantly</td>
<td>Pre-operative</td>
</tr>
<tr>
<td>Social support for donation</td>
<td>The people closest to me support my decision to be a living donor</td>
<td>Strongly Disagree, Disagree, Neither Agree or Disagree, Agree, Strongly Agree</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recovery from Surgery</td>
<td>Complications</td>
<td>Did you have any complications once you were discharged from hospital? If yes, what complication/s did you have? (please tick all that apply) Did any of these complications require further admissions to hospital Did any of these complications require further surgery? Have you been prescribed ANTIBIOTICS by anyone after surgery? (This can be your GP, the Guy’s team or another doctor) If yes, what were the antibiotics prescribed for?</td>
<td>Yes / No, Severe pain, Infection, Wound, Urine, Chest, Unknown source, Hernia, Other</td>
<td>3 months</td>
</tr>
<tr>
<td>Qualitative Theme</td>
<td>Question Theme</td>
<td>Questions written</td>
<td>Possible answers</td>
<td>Time point</td>
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</tr>
<tr>
<td>Recovery from Surgery</td>
<td>Over the past 12 months have you had any NEW medical or surgical problems related to your donor operation?</td>
<td>Yes / No</td>
<td>12 months</td>
<td></td>
</tr>
<tr>
<td></td>
<td>If yes, what new medical or surgical problem have you had?</td>
<td>High blood pressure, Urinary symptoms, Severe pain, Hemia, Other - please state</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Over the past 12 months have you been admitted to hospital with any medical or surgical problem related to your donor operation?</td>
<td>Yes / No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Return to work and driving</td>
<td>If you are currently working, how much time did you have off before returning to work?</td>
<td>(I am not currently working / I do not drive, Less than 4 weeks, 4-6 weeks, 6-12 weeks, More than 12 weeks)</td>
<td>3 months</td>
<td></td>
</tr>
<tr>
<td>Return to normal</td>
<td>When did you feel back to your normal self?</td>
<td>___ weeks / I do not feel back to my normal self yet</td>
<td>3 months</td>
<td>12 months</td>
</tr>
<tr>
<td>Whether experience of donation matched expectations</td>
<td>Was the experience of donating (including the pre-operative workup, operation, hospital stay and recovery)</td>
<td>Much better than expected, Better than expected, The same as expected, Worse than expected, Much worse than expected</td>
<td>3 months</td>
<td></td>
</tr>
<tr>
<td>Residual pain at operative site</td>
<td>How much on-going pain do you have as a result of your operation?</td>
<td>0-10 scale provided, anchored with &quot;No pain&quot; and &quot;Pain as bad as it could be&quot;</td>
<td>3 months</td>
<td>12 months</td>
</tr>
<tr>
<td>Recipient complications</td>
<td>Did your recipient have any complications immediately after their surgery?</td>
<td>Yes / No / Unsure</td>
<td>3 months</td>
<td></td>
</tr>
<tr>
<td></td>
<td>If yes, what complications did they have? (select all that apply)</td>
<td>Rejection, Re-operation, Severe infection, Loss of Kidney, Other major / minor complication, Other – please state</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Did your recipient require any dialysis after the transplant took place?</td>
<td>Yes / No / Unsure</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Is your recipient still alive? Has your recipient had any complications after their kidney transplant?</td>
<td>Yes / No / Unsure</td>
<td></td>
<td>12 months</td>
</tr>
<tr>
<td>Qualitative Theme</td>
<td>Question Theme</td>
<td>Questions written</td>
<td>Possible answers</td>
<td>Time point</td>
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<td>------------------------------------------</td>
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<td>------------</td>
</tr>
<tr>
<td>Recovery from Surgery</td>
<td>If yes, what complications have they had? (Please select all that apply)</td>
<td>(Rejection, Another operation, Severe infection/s requiring admission to hospital, Other major complication, Other minor complication, Other - please state)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Is the kidney still working? Has your recipient required any dialysis since the transplant took place?</td>
<td></td>
<td>Yes / No / Unsure</td>
<td></td>
</tr>
<tr>
<td>Regret</td>
<td>Current regret</td>
<td>If I had my time again I would not choose to be a Living Kidney Donor*</td>
<td>Strongly Disagree, Disagree, Neither Agree or Disagree, Agree, Strongly Agree</td>
<td>3 months</td>
</tr>
<tr>
<td></td>
<td>Anticipated regret</td>
<td>I will continue to feel the same way about being a Living Kidney Donor regardless of what happens in the future</td>
<td>Strongly Disagree, Disagree, Neither Agree or Disagree, Agree, Strongly Agree</td>
<td>12 months</td>
</tr>
<tr>
<td>Life after the Transplant</td>
<td>Post-operative relationship with recipient and others</td>
<td>On the whole, my relationship with my recipient is better now than before the transplant</td>
<td>Strongly Disagree, Disagree, Neither Agree or Disagree, Agree, Strongly Agree</td>
<td>3 months</td>
</tr>
<tr>
<td></td>
<td>On the whole, my relationships with other people around me are better now than before the transplant</td>
<td></td>
<td></td>
<td>12 months</td>
</tr>
<tr>
<td>Donation as a life event</td>
<td>How donation compares to other life events</td>
<td>Donating a kidney is one of the best things I have ever done</td>
<td>Strongly Disagree, Disagree, Neither Agree or Disagree, Agree, Strongly Agree</td>
<td>3 months</td>
</tr>
<tr>
<td></td>
<td>Feelings towards donation</td>
<td>I feel good about being a Living Kidney Donor</td>
<td>Strongly Disagree, Disagree, Neither Agree or Disagree, Agree, Strongly Agree</td>
<td>12 months</td>
</tr>
<tr>
<td></td>
<td>Attitudes of others towards donor and the importance of receiving praise</td>
<td>I have been praised for being a Living Kidney Donor</td>
<td>Strongly Disagree, Disagree, Neither Agree or Disagree, Agree, Strongly Agree</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Being praised for being a Living Kidney Donor</td>
<td>Being praised for being a Living Kidney Donor is not important to me*</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Effect on self-esteem</td>
<td>Being a Living Kidney Donor has improved my self-esteem (how I see myself)</td>
<td>Strongly Disagree, Disagree, Neither Agree or Disagree, Agree, Strongly Agree</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Effect on life perception</td>
<td>Being a Living Kidney Donor has changed my outlook on life</td>
<td>Strongly Disagree, Disagree, Neither Agree or Disagree, Agree, Strongly Agree</td>
<td></td>
</tr>
</tbody>
</table>

* Reverse scored
content validity tests were performed in order to ensure that no additional factors had been missed.

More empirical forms of validity are also necessary in order to provide further evidence in support of the newly devised questionnaire. The methods used will depend on whether a same or similar scale is available for direct comparison. If a same or similar scale is available, the new questionnaire can undergo a number of different types of validation including convergent, criterion and concurrent validation. Unfortunately for this study, no similar scale was available for use and this is principally the reason for writing new questions in the first instance. Where no similar measure exists, empirical validity testing can still be performed by linking the attribute that the new question is aiming to measure to some other attribute by hypothesis or construct. This approach is called construct validity (Streiner and Norman, 2008).

Face and content validity testing was performed by a range of clinicians within the field of transplantation, academics within the field of health psychology, pre- and post-operative living kidney donors and medical administrative personnel. The 13 clinicians included 2 consultant nephrologists, 2 consultant transplant surgeons, 5 living donor co-ordinators, 2 transplant nurses, a consultant psychiatrist and a renal clinical psychologist.

Additionally, the 5 health psychologists included 1 professor, 2 PhD students and 2 lecturers. Individuals were asked whether the questions made sense and were easy to read. They were asked to describe what they thought each question was trying to ask and whether they thought the question theme would be acceptable. They were also asked whether the responses provided for answering the questions appeared reasonable, were easy to understand and sensible. No additional themes or topics were suggested for inclusion. Following minor changes the questions then underwent further face and content validity testing by pre- and post-operative donors, their relatives and medical administrative staff.

Pre-operative donors (8 donors) were recruited from the living donor transplant education session which takes place each week in the renal clinic at Guy’s Hospital. Donors attend this session 2 weeks prior to their scheduled surgery. It was important to seek the opinion of donors at this stage of the donation process in particular because the same education session had already been identified as the main opportunity to subsequently recruit donors once the study was live. The post-operative donors (12
donors) included in-patients who had just donated and those attending the annual donor follow up clinic held fortnightly in the renal outpatient department. All donors were shown the questionnaire in its entirety, including the 12 validated measures followed by the new questions. All found the questionnaire acceptable in terms of content and length and expressed an interest in taking part had they been approached. All participants were able to select an appropriate answer from the list provided. On 10 occasions, where time permitted, donors completed the questionnaire to assess an average completion time. The mean completion time was 27 minutes (range 19-45 minutes). The 5 medical administrative staff included medical secretaries from the renal department and members of the clerical clinic team.

Only a handful of questions were deemed suitable for construct validity testing, which took place once the study had completed recruiting, as a large sample size was unfeasible in the questionnaire development phase of the thesis. The questions tested and correlation statistics are listed in Table 4.3. These tests demonstrate that those questions which asked specifically about the donor’s anxiety related to different aspects of their donation also demonstrated higher levels of anxiety on the validated measure used (the State-Trait Anxiety Inventory). The question written to establish whether living donation had had an impact on the individuals self-esteem and social comparison also correlated highly with the validated measures used (the Rosenberg Self-Esteem Scale and the Social Comparison Scale, respectively).

Only minor modifications were necessary prior to finalisation. These included replacing some terms such as “infrequently” or “often” with time points, such as “weekly” or “daily”, in order to make the questions easier to answer. Ambiguous terms were removed or replaced accordingly. Additional answers were added in order to minimise missing data, such as “I do not know”; which was preferable to missing data in the event of a participant being unable to answer a question. Face and content validity testing took place over a 6 week period.
### Table 4.3: Questions tested for construct validity

<table>
<thead>
<tr>
<th>Question Written</th>
<th>Psychosocial attribute</th>
<th>Correlated against</th>
<th>N</th>
<th>r</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pre-operative questionnaire</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Since you first agreed or decided to donate how often have you thought about it?</td>
<td>Anxiety</td>
<td>STAI-short</td>
<td>100</td>
<td>0.326</td>
<td>0.001*</td>
</tr>
<tr>
<td>Since deciding to be a Living Kidney Donor, how often have you thought about:</td>
<td>Anxiety</td>
<td>STAI-short</td>
<td>100</td>
<td>0.432</td>
<td>&lt;0.001*</td>
</tr>
<tr>
<td>The process you will have to go through?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Since deciding to be a Living Kidney Donor, how often have you thought about:</td>
<td>Anxiety</td>
<td>STAI-short</td>
<td>95</td>
<td>0.399</td>
<td>&lt;0.001*</td>
</tr>
<tr>
<td>Your social circumstances and how these may be affected by donating?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>When thinking about your RECIPIENT, how much do you worry about something going wrong or the transplant being unsuccessful?</td>
<td>Anxiety</td>
<td>STAI-short</td>
<td>100</td>
<td>0.479</td>
<td>&lt;0.001*</td>
</tr>
<tr>
<td><strong>Post-operative questionnaire</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being a Living Kidney Donor has improved my self-esteem (how I see myself)†</td>
<td>Self-esteem</td>
<td>Rosenberg</td>
<td>30</td>
<td>0.607</td>
<td>0.003*</td>
</tr>
<tr>
<td></td>
<td>Social comparison</td>
<td>SCS</td>
<td>30</td>
<td>0.454</td>
<td>0.029*</td>
</tr>
</tbody>
</table>

*p<0.05  
† This question was correlated against the different in self-esteem between baseline and 3 months

**Abbreviations:** SCS: Social Comparison Scale; STAI-short: 6 item State-Trait Anxiety Inventory

### Reliability testing

Reliability testing was undertaken when the study was live and had started recruiting. Reliability testing is necessary in order to determine whether a questionnaire is measuring something in a reproducible fashion. Reliability is expressed as a number between 0 and 1, where 0 implies no reliability and 1 implies perfect reliability. As with validity, there are a number of ways that reliability can be tested. Internal consistency assesses the degree of correlation between different questions exploring the same construct and is often measured using a Cronbach’s alpha. It follows that in
order to measure internal consistency more than one question addressing a particular
construct is needed within a questionnaire. Due to the need to keep the number of
questions to a minimum, most concepts within the new questions were measured
using a single item. However, a number of items were included to ascertain to what
extent different aspects of the living donation process were on the donor’s mind pre-
operatively; the so-called ‘thoughts of living donation’ scale. These aspects included
thinking about the decision to donate, the process of donation, the social circumstances
of donation and worrying about the recipient. The scale was found to have a high level
of internal consistency, as determined by a Cronbach’s alpha of 0.747.

Stability, or reproducibility, can be measured differently, depending on the intended
use for the questionnaire. Inter-observer reliability provides the level of agreement
between 2 independent raters at the same time point, whereas intra-observer
reliability provides the level of agreement between observations made by the same
individual at 2 different time points. The most appropriate test for this questionnaire
was for test-retest reliability, which assesses the level of agreement between answers
given by the same individual over 2 or more time-points. This provides an assessment
of the extent to which questionnaire answers are repeatable when completed by the
same individual.

Test-retest reliability testing was not possible for the pre-operative questionnaire due
to difficulties encountered with recruitment. In order to complete the questionnaire on
2 separate occasions prior to surgery it was necessary for the donor to be recruited a
minimum of 4 weeks prior to surgery in order that written informed consent could be
given prior to questionnaire completion. Due to donors only being listed for surgery
after all their tests had been completed this meant that very rarely would a donor
attend the hospital so far from their operation date. A further condition of the ethics
approval was that donors would not be asked to attend appointments solely for the
purposes of research, given the large number of visits they would have made as part of
the donation process. This therefore meant that the earliest opportunity to obtain
consent from a participant was commonly just 2 weeks prior to their surgery. This left
insufficient time for the questionnaire to be completed on 2 occasions with an
appropriate gap in-between.

Test-retest reliability testing was performed on the post-operative questionnaire at 3
months. 30 participants completing the 3 month questionnaire were asked to
complete the questionnaire on a second occasion 2 weeks later. A 2 week interlude
was chosen so to minimise the chances of participants remembering what they answered on the first occasion, and then simply repeating the same answers from memory. A 2 week period at 3 months would also be a relatively stable time-point in both the donor and recipient’s recovery, thereby minimising the chances of there being a significant event between the two time-points which could otherwise account for differences in the answers given. The test-retest results are provided in Table 4.4 and reflect a correlation between scores given at 3 months and 3 months plus 2 weeks. The results demonstrate a large correlation (>0.7) for the majority of items and medium correlation for 4 items. Only 1 item was of low correlation and was not statistically significant (“On the whole, my relationships with other people around me are better now than before the transplant”).

Table 4.4: Questions tested for test-retest reliability

<table>
<thead>
<tr>
<th>Question</th>
<th>r value</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>My recipient’s DAY-TO-DAY life is much better now than before the transplant</td>
<td>0.927</td>
<td>&lt;0.001*</td>
</tr>
<tr>
<td>My own DAY-TO-DAY life is much better now than before the transplant</td>
<td>0.753</td>
<td>&lt;0.001*</td>
</tr>
<tr>
<td>The DAY-TO-DAY lives of other people around me are better now than before the transplant</td>
<td>0.456</td>
<td>0.033*</td>
</tr>
<tr>
<td>On the whole, my relationship with my recipient is better now than before the transplant</td>
<td>0.813</td>
<td>&lt;0.001*</td>
</tr>
<tr>
<td>On the whole, my relationships with other people around me are better now than before the transplant</td>
<td>0.336</td>
<td>0.117</td>
</tr>
<tr>
<td>Donating a kidney is one of the best things I have ever done</td>
<td>0.780</td>
<td>&lt;0.001*</td>
</tr>
<tr>
<td>I feel good about being a kidney donor</td>
<td>0.590</td>
<td>0.004*</td>
</tr>
<tr>
<td>If I had my time again I would not choose to be a Living Kidney Donor</td>
<td>0.692</td>
<td>&lt;0.001*</td>
</tr>
<tr>
<td>I have been praised for being a Living Kidney Donor</td>
<td>0.901</td>
<td>&lt;0.001*</td>
</tr>
<tr>
<td>Being praised for being a Living Kidney Donor is not important to me</td>
<td>0.446</td>
<td>0.033*</td>
</tr>
<tr>
<td>Being a Living Kidney Donor has improved my self-esteem (how I see myself)</td>
<td>0.884</td>
<td>&lt;0.001*</td>
</tr>
<tr>
<td>Being a Living Kidney Donor has changed my outlook on life</td>
<td>0.770</td>
<td>&lt;0.001*</td>
</tr>
<tr>
<td>I will continue to feel the same way about being a Living Kidney Donor regardless of what happens in the future</td>
<td>0.495</td>
<td>0.016*</td>
</tr>
</tbody>
</table>

*p<0.05
**Conclusion of validity and reliability testing**

Although it was not possible to assess all aspects of validity and reliability for the new questions, analyses that were conducted indicated that they reasonably measured the concepts that were intended. Very few modifications were required following face and content validity tests. Construct validity tests demonstrated medium or large correlations against the formerly validated anxiety, self-esteem and social support measures, all of which were statistically significant. The opportunity to perform internal consistency tests were limited, however when done so demonstrated a high level of internal consistency with a Cronbach’s alpha of 0.747. There was also good test-retest reliability, with the majority of measures demonstrating a medium or large correlation between the 2 time points.

**Demographic questions**

These questions were placed at the end of the questionnaire and covered ethnicity, religious beliefs, highest level of education, employment status, relationship status and number of children and adult dependents. Donors were additionally asked about whether their religious beliefs had been of importance or relevance in their decision to become a living donor.

Additional demographic data was obtained by interrogating the Electronic Patient Records (EPR) system at Guy’s Hospital and by asking the donor in private at the time of recruitment. Questions enquired about what the relationship between the donor and recipient was and whether the donor was the primary caregiver of their recipient. Primary caregiver status was defined as someone who participated in the everyday care of the recipient, someone who was the first point of contact in the event of a medical emergency or someone who routinely assisted the recipient with health related tasks, such as attendance to hospital appointments. Donors were additionally asked whether the transplant was blood group and immunologically compatible and whether they were donating directly to their recipient or donating as part of a chain or paired-exchange. A full medical, surgical and mental health history was then taken. Details regarding treatment of mental health conditions were taken, alongside asking whether the individual had been referred to see a psychologist or psychiatrist as part of their workup. Recipient details included dialysis status and duration and number of previous transplants.
Recruitment

Eligibility Criteria

All participants were recruited from Guy’s Hospital, London. All living kidney donors donating between August 2012 and August 2013 were eligible for inclusion. Donors had to be aged 18 or over and must have been able to read and understand English without the use of an interpreter. This was because of the complexity of the questionnaire and the possibility of miscommunication or misinterpretation of questions and answers when obtained through an interpreter. In addition, English-speaking participants would complete the questionnaires independently without a healthcare professional being present in order to encourage honesty and discourage the giving of answers that were socially acceptable but untrue. It was important that all participants completed the questionnaire in the same way and therefore those unable to complete it independently were excluded. Unspecified donors and those donating as part of a chain or exchange programme were also included. Donors needed to have attended the hospital on at least one occasion between the completion of their workup investigations and appointments and the date of surgery in order to be consented.

Approval from NHS research ethics and the research and development departments were received (Reference numbers: 09/H0804/31 and RJ109/N126).

Identification of potential participants

Potential participants were identified from a list held by the living donor matron. Dates for surgery are most commonly allocated on a ‘next available’ basis, on average a month to six weeks in advance. Donor and recipient requests are accommodated as much as possible. More complex patients may require a particular surgeon with certain expertise and in these cases a mutually convenient date is agreed. Unspecified donors and those donating as part of a chain or exchange programme must be coordinated with the recipient centre (in the case of unspecified donation) and with the other centres participating the chain or exchange. The living donor transplant list was reviewed on a weekly basis in order to identify potential study participants at the earliest opportunity.

Study introduction and consent

Prior to their scheduled date, donors and recipients were required to attend a final appointment with their living donor specialist nurse 2 weeks prior to scheduled
surgery. At this appointment a final set of routine blood tests were taken to confirm that the donor was still fit to donate. On the same day, donors and recipients were required to attend an education session held by one of the living donor specialist nurses and a pre-operative assessment by a junior member of the surgical team. The education session, typically 60-90 minutes in duration, outlined the final details of the admissions process, what the donor and recipient should expect whilst in hospital and the particular details of the recovery process. Although many of the topics and issues discussed at this session would have been discussed previously, they are revisited and there is a further opportunity for the donor to ask questions prior to surgery. Wherever possible potential participants were contacted by telephone in advance of the education session and were mailed a patient information sheet. The study was then formally introduced by a single researcher (NHM) prior to the start of the education session and any immediate questions were answered. Following the education session the researcher returned to the group and answered any further questions about the study.

Formal written consent was then taken from willing participants in a private consultation room by the researcher. Basic demographic details and a brief medical, surgical and mental health history was also taken at this time. Participants were given the option of completing the questionnaire on paper whilst in the hospital or completing it at home, either online or on paper. Where questionnaires were taken away from the clinic and completed on paper, a stamped return envelope was provided. Most commonly participants opted to complete the questionnaire online. In these instances the researcher contacted the recipients by email and sent them a link to the Bristol Online Survey. The Bristol Online Survey provides a secure, encrypted online environment in which to complete questionnaires. The software permits the use of unique usernames and passwords which means that individuals are identifiable to the research team without having to enter any sensitive identifiable information, such as their name or date of birth. Participants were followed up with a telephone call in the event that questionnaires had not been completed within 5 days of consent having been taken. The donors’ General Practitioner (GP) was notified of their involvement by post and was sent a copy of the patient information sheet. A copy of the GP letter, the consent form and the patient information sheet was filed in the donors’ paper notes. An entry notifying the clinical team of the donors’ involvement in the study was also made on the EPR system.
Inpatient experience and follow up procedure

After the education session the donor is not required to attend the hospital until the morning of their operation. Donors were visited by NHM on the day of surgery and each post-operative day wherever possible, including weekends where feasible. Some donors additionally consented to participating in a wound healing study that utilised high resolution ultrasound to make an assessment of the relationship between stress, personality and post-operative wound healing. These donors were always visited on days 1, 2 and 3 by a member of the research team. This study is outlined in chapter 6.

Donors are deemed fit to be discharged when their pain is controlled on oral medications and when they are mobilising independently. Following discharge, donors are reviewed in the surgical outpatient clinic 2-4 weeks after surgery. They are reviewed by a consultant surgeon or surgical registrar who takes a brief history of their recovery to date and examines their abdomen. Blood, urine and blood pressure checks are also performed. Donors were also visited by the research team and were reminded to expect a questionnaire 3 months after their donation.

Should a donor encounter a medical or surgical issue prior to their scheduled follow up appointment they are advised to contact their living donor specialist nurse during office hours or the surgical ward out-of-hours. Depending on the nature of the issue and where they live in relation to the hospital, they are advised to attend the surgical clinic early, to attend the ward or, if the issue is an emergency, go to their local accident and emergency department. Their case is then subsequently discussed with a consultant surgeon prior to a management plan being devised. Those donors requiring additional investigations are either admitted or are advised to return as an outpatient, whichever is appropriate.

After the initial follow up period donors are next reviewed 12 months after their surgery in a nurse-led clinic at Guy's Hospital, a transplant clinic at the referring hospital (if the donor was referred from another centre) or by the donor's GP. Donors undergo formal review and examination, blood and urine tests and weight and blood pressure checks. Where issues or complications arise donors are referred for further investigations or to the surgical clinic for review by a consultant surgeon. If the donor has no new issues they are then seen annually for the following 5 years and then every 2 years thereafter.
The follow up questionnaires were completed at 3 and 12 months. Donors were sent
the questionnaire either by email or by post. Those donors who did not respond to
initial contact were reminded either by email or telephone after 1 week. Those donors
who were not responding to email were subsequently called and a paper copy sent in
the post. All postal questionnaires were sent with a stamped addressed return
envelope. Acknowledgements of returned questionnaires were sent immediately after
replies were received. The nurse-led annual follow up clinic was attended by the
researcher wherever possible. This was to formally thank the donor for participating
in the study and was a further opportunity to remind participants to complete the
questionnaire in the event it had not been completed. Donors were again offered the
opportunity to complete the questionnaire on paper in the clinic or complete it at
home.

Data handling
All patient identifiable data was stored on a password protected Microsoft Excel file
which in turn was stored on an encrypted memory stick accessible only by the main
researcher (NHM). Questionnaires completed online on the Bristol Online Survey
(BOS) website were downloaded directly into an excel spreadsheet. This meant the
there was no possibility of a transcription error affecting the study results. Those
questionnaires completed on paper were transcribed by NHM into the BOS by using the
unique patient identifier and password allocated to each individual participant. All
paper questionnaires were checked prior to analysis of the data to ensure that no
transcription errors had occurred. Paper questionnaires were labelled with the
participant’s unique identification number and stored in a locked office within the
Clinical Transplant Laboratory at Guy's Hospital. The data was then coded prior to
importation into SPSS (IBM; version 22).

Statistical Methodology
The statistical package IBM SPSS Version 22 was used for all statistical analyses. Data
were assessed for normality by visual inspection of graphs and, on occasions where
distribution was not obvious, numerically through the use of the Shapiro-Wilk test.
Independent samples t-tests and one-way ANOVA were used to test between
independent groups on occasions when the data were normally distributed. Mann-
Whitney and Kruskal Wallis tests were used to test between independent groups on
occasions where the data were not normally distributed.
Pearson and Spearman correlations were used for correlating 2 continuous variables for parametric and non-parametric data, respectively. Repeated measures for parametric data were assessed using a paired samples t-test when the independent variable consisted of 2 groups and a within groups ANOVA when the independent variable consisted of more than 2 groups. Repeated measures for non-parametric data were assessed using the Wilcoxon Signed Rank test when the independent variable consisted of 2 groups and the Friedman test when the independent variable consisted of more than 2 groups.

A mixed ANOVA was used for parametric data to compare the mean difference in questionnaire scores over the 3 questionnaire time points between 2 or more independent groups. A related-samples Friedman's Two-Way Analysis of Variance by Ranks test was used for non-parametric data.
Chapter 5
Longitudinal study of Psychosocial Outcomes: Results and Discussion

Chapter summary
This chapter is divided into 3 sections.

Section 1 provides details of recruitment rates and descriptive participant data (participant demographics, medical, surgical and mental health histories, transplant details and recipient demographics). Analysis of the responses given to the pre-operative questionnaire, including the 11 psychosocial questionnaires and the donation-specific questions, are also outlined. This section corresponds to the first hypothesis of the study: that there are a number of donor and transplant-related factors that will be associated with poorer than average psychosocial questionnaire scores pre-operatively. These factors include: donating to one of your own children (parental donor), being a primary caregiver to the recipient, being asked to donate, being the only available donor, donating to a recipient on dialysis and donating to a recipient who is thought to be unwell.

Section 2 contains an analysis of the 3 and 12 month questionnaire scores for each of the psychosocial measures used in the study and the post-operative donation-specific questions. This section corresponds to the second hypothesis of the study: that on average, scores across a number of measures will show an improvement after donation (wellbeing, life satisfaction, self-esteem and social comparison, distress, depression, stress and anxiety) and that some will be the same by 12 months (physical health-related quality of life, social support and optimism).

Section 3 contains a sub-analysis of the 3 questionnaires, looking in more detail at whether different groups of donors display different trajectories of psychosocial recovery after donation. This section corresponds to the third hypothesis of the study: that the psychosocial wellbeing of a subset of donors will improve after donation and a subset will decline. Parents and primary caregivers were expected to demonstrate an improvement whilst the following groups of donors were expected to demonstrate a decline: donors who experienced post-operative complications, donors whose recipients experienced post-operative complications, recipient death or graft loss and donors whose relationship with their recipient had deteriorated after donation.
Section 1

Recruitment

115 living kidney donors donated at Guy’s Hospital between August 2012 and August 2013. Of these, 6 did not meet the inclusion criteria and were therefore not approached to participate in the study: 3 were non-English speakers and 3 had their transplant scheduled less than a week prior to surgery so were unable to be recruited within the required pre-operative timeframe. The remaining 109 living kidney donors were invited to participate, 5 of whom declined: 3 were uninterested in the study and 2 felt that they were unable to participate due to concurrent commitments. 104 donors were therefore recruited (95.4% of those meeting the inclusion criteria). Four donors failed to complete a questionnaire prior to surgery: 3 had their operations cancelled before the questionnaire was completed (2 due to the recipient being unfit for transplantation, 1 due to the donor being unfit for donation because of abnormal blood tests) and 1 withdrew consent after seeing the questionnaire because she felt the questions were too intrusive. Pre-operative questionnaires from 100 donors were therefore obtained and are included in the analysis. All questionnaires were self-completed.

Table 5.1 outlines the demographic details of the 100 participants who completed a pre-operative questionnaire. 7 participants did not proceed to donation: 4 recipients were medically unfit for transplantation (diagnosed with anaemia, recurrent infections, sepsis and pulmonary embolism), 2 donors were medically unfit to donate immediately before their scheduled surgery (diagnosed with liver disease and kidney stones). 1 donor withdrew from the donation process because she changed her mind about wanting to donate.

Participant data

Participant Demographics (Table 5.1)

Fifty-five men and 45 women participated in the study. The average age was 45 years (SD 12.98; Range 18-70) and there was no significant difference in age between men and women (t (98) = -1.05, p=0.296, 95% CI [-7.913, 2.434], d=2.8 years). The majority of donors were white (82%) and stated their religious beliefs as Christian (54%). Of those with religious beliefs, 72.6% reported that their religious beliefs were unimportant when making the decision to become a living donor. The majority of donors had completed higher education (42%) and were working at the time of their donation (82%). The pre-operative questionnaire was most commonly completed at
Table 5.1: Demographic data

<table>
<thead>
<tr>
<th>Variable</th>
<th>Statistic (n=100)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>55</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>45</td>
<td></td>
</tr>
<tr>
<td>Mean age at donation (years (SD))</td>
<td>45.0 years (12.98)</td>
<td></td>
</tr>
<tr>
<td>Mean age at donation (years (SD))</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>43.7 years (13.44)</td>
<td>0.296</td>
</tr>
<tr>
<td>Female</td>
<td>46.5 (12.37)</td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
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</tr>
<tr>
<td>White</td>
<td>82</td>
<td></td>
</tr>
<tr>
<td>Non-white</td>
<td>18</td>
<td></td>
</tr>
<tr>
<td>Religious Beliefs</td>
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<td></td>
</tr>
<tr>
<td>No religious beliefs</td>
<td>35</td>
<td></td>
</tr>
<tr>
<td>Christian</td>
<td>54</td>
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</tr>
<tr>
<td>Muslim</td>
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<tr>
<td>Hindu</td>
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<tr>
<td>Buddhist</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td></td>
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<tr>
<td>Missing data</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Highest Qualification</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No qualifications</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>School leaver</td>
<td>17</td>
<td></td>
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<td>College level</td>
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<td>Higher education</td>
<td>42</td>
<td></td>
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<tr>
<td>Other</td>
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<td></td>
</tr>
<tr>
<td>Missing data</td>
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<td></td>
</tr>
<tr>
<td>Employment status at the time of donation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not currently working</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Employed / in education</td>
<td>65</td>
<td></td>
</tr>
<tr>
<td>Self-employed</td>
<td>17</td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Missing data</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Relationship status at the time of donation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>22</td>
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</tr>
<tr>
<td>Married or long-term partner</td>
<td>70</td>
<td></td>
</tr>
<tr>
<td>Divorced / Separated</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Missing data</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Variable</td>
<td>Statistic (n=100)</td>
<td>P value</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>-------------------</td>
<td>---------</td>
</tr>
<tr>
<td>Children</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>70</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>30</td>
<td></td>
</tr>
<tr>
<td>Minors in household</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>32</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>68</td>
<td></td>
</tr>
<tr>
<td>Other dependents (aged &gt; 18)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>87</td>
<td></td>
</tr>
<tr>
<td>Missing data</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Donor base hospital</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Guy's Hospital</td>
<td>53</td>
<td></td>
</tr>
<tr>
<td>King's College Hospital</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>Kent and Canterbury</td>
<td>16</td>
<td></td>
</tr>
<tr>
<td>Channel Islands</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>17</td>
<td></td>
</tr>
<tr>
<td>Pre-operative day questionnaire completed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median</td>
<td>- 11 days</td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>(-1 to 27 days)</td>
<td></td>
</tr>
<tr>
<td>Location of questionnaire completion</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home</td>
<td>67</td>
<td></td>
</tr>
<tr>
<td>Clinic</td>
<td>33</td>
<td></td>
</tr>
<tr>
<td>Modality of questionnaire completion</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paper</td>
<td>47</td>
<td></td>
</tr>
<tr>
<td>Online</td>
<td>53</td>
<td></td>
</tr>
</tbody>
</table>
home (67%), 11 days prior to surgery (Mdn score presented; IQR = 7; range = -1 days to -27 days).

The majority of donors had their workup conducted at Guy's Hospital (53%). 30% were referred from centres within the Guy's Hospital catchment area for transplantation (King's College and Kent and Canterbury Hospitals or the Channel Islands). The remaining 17% included tertiary referrals or donors who had had their workup performed elsewhere in the UK, but whom were donating to a recipient based at Guy's Hospital or within the Guy's Hospital catchment area. Six donors were from overseas, donating to recipients who were all based in the UK. They were from the following countries: Nigeria (2), The Gambia (1), Germany (1), New Zealand (1) and Poland (1).

Medical, surgical and mental health history (Table 5.2)
Forty-six donors had a medical history which included the following: hypertension (10), bone and joint problems (9), renal cysts, stones and other urological issues (9), asthma (5), hypercholesterolaemia (4), gynaecological (cervical dysplasia, fibroids, endometriosis) (3), thyroid dysfunction (3), gastrointestinal problems (diverticulitis, gastro-oesophageal reflux disease, perforated duodenal ulcer) (3), iron deficiency anaemia (2), malaria (2), tuberculosis (2), ophthalmological problems (glaucoma, macular degeneration) (2), dermatological condition (2), Gilbert's syndrome (1), rheumatic fever (1), fibromyalgia (1), migraines (1) and cardiac arrhythmia (1). 13 donors were cigarette smokers at the time of donation.

Sixty-three donors had a surgical history, which included the following: orthopaedic procedure including joint arthroscopy (24), gynaecological procedure (including in-vitro fertilisation, caesarean section and termination of pregnancy) (19), Ear Nose and Throat procedure (18), appendicectomy (11), urological procedure (9), Hernia repair (6), excision of skin lesion (6), varicose vein procedure (3), breast implants (3), thyroid procedure (removal of benign nodules, lobectomy) (2), cholecystectomy (2), gastrointestinal (emergency laparotomy for perforated duodenal ulcer, anal surgery) (2), maxillofacial surgery (1), nerve root decompression (1) and an ophthalmological procedure (1).

2 The commonest reason for a tertiary referral to Guy's Hospital is so that an incompatible transplant can take place or because the transplant is high risk for medical, surgical or immunological reasons.
<table>
<thead>
<tr>
<th>Variable</th>
<th>Statistic (n=100)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Past medical history</td>
<td></td>
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<tr>
<td>Yes</td>
<td>46</td>
</tr>
<tr>
<td>No</td>
<td>54</td>
</tr>
<tr>
<td>Past surgical history (procedure requiring General anaesthetic)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>63</td>
</tr>
<tr>
<td>No</td>
<td>37</td>
</tr>
<tr>
<td>Past or current mental health illness</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>27</td>
</tr>
<tr>
<td>Received treatment (therapy / medications)</td>
<td>27 (100%)</td>
</tr>
<tr>
<td>Were seen by a psychologist / psychiatrist pre-operatively</td>
<td>20 (74.1%)</td>
</tr>
<tr>
<td>On antidepressants at the time of donation</td>
<td>6</td>
</tr>
<tr>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Were seen by a psychologist / psychiatrist pre-operatively</td>
<td>72</td>
</tr>
<tr>
<td>Missing data</td>
<td>18 (25%)</td>
</tr>
<tr>
<td>Smoking status</td>
<td></td>
</tr>
<tr>
<td>Current smoker</td>
<td>13</td>
</tr>
<tr>
<td>Non-smoker</td>
<td>87</td>
</tr>
<tr>
<td>BMI</td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>26.1 (3.95)</td>
</tr>
<tr>
<td>Pre-operative Blood results</td>
<td></td>
</tr>
<tr>
<td>Creatinine (umol/L) (Mean, SD)</td>
<td>82.8 (1.69)</td>
</tr>
<tr>
<td>eGFR (mL/min) (Mean, SD)</td>
<td>87.2 (15.9)</td>
</tr>
<tr>
<td>CRP (mg/L)</td>
<td></td>
</tr>
<tr>
<td>&lt; 5 (not inflamed)</td>
<td>93</td>
</tr>
<tr>
<td>&gt; 5 (inflamed)</td>
<td>7</td>
</tr>
</tbody>
</table>

Twenty-seven donors disclosed a history of mental health illness to the researcher (NHM). All 27 had sought professional help and had been treated either with a therapeutic intervention and / or pharmacologically. Mental health problems included: depression (including nervous breakdown, post-natal depression and a suicide attempt) (22), anxiety (including panic attacks) (8), and a stress disorder (1). Of the 27 donors with a mental health history, 7 received no mental health review prior to donation (25.9%). Six had a history of depression and 1 had a history of anxiety. The Electronic Patient Record (EPR) was interrogated to identify possible reasons why a mental health referral was not made pre-operatively. One donor had disclosed a
history of depression during his nephrology appointment but was not referred because the consultant nephrologist did not think it was necessary. In the remaining 6 cases, no documentation of a mental health illness was found anywhere in the medical notes. As there was no reference to mental health history in the notes it was not possible to determine whether donors had ever been asked about their mental health history, or whether they had been asked but had denied any mental health problems.

Six donors were taking anti-depressant medications at the time of donation and 1 of these received no psychological review pre-operatively. This was the same donor who was not referred on the advice of the consultant nephrologist. Of those with no mental health background (72 donors), 18 were seen by a psychologist or psychiatrist as part of their work up (25%). The reasons for this were not ascertainable from the medical notes.

Of interest, in 60 cases there was no documentation of donors having been asked about their mental health history by a transplant co-ordinator, a nephrologist or a transplant surgeon. Only 8 donors were asked about their mental health history by all 3 transplant professionals. In 77 cases there was no documentation of donors having been asked about their current mental health. Only 1 donor was asked about their current mental health by all 3 transplant professionals.

Transplant details and recipient demographics (Table 5.3)
The majority of donors (91%) made a direct donation to a specific, identified recipient. Four donors donated as part of the paired or pooled donation scheme and 5 were unspecified donors. Twenty donor-recipient pairs (21.9%) were either blood or tissue type incompatible. The modal donor-recipient relationship group was parent donating to one of their children (38 donors) and of these donations, 19 were to children under the age of 18. Donors were the primary caregiver of their recipient in 43 cases. The average age of adult recipients was 43.3 years (SD 15.09) and of child recipients was 7.6 years (SD 5.0). Fifty-two recipients were male and 43 were female. The majority of recipients were receiving their first transplant and were on dialysis at the time of their transplant (average duration: 3.8 years (SD 3.15)).
Table 5.3: Transplant details and recipient demographics

<table>
<thead>
<tr>
<th>Variable</th>
<th>n / %</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of donation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Direct</td>
<td>91</td>
<td></td>
</tr>
<tr>
<td>Paired / pooled donation</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Unspecified</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td><strong>Type of transplant compatibility</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Compatible transplant</td>
<td>80</td>
<td></td>
</tr>
<tr>
<td>Incompatible transplant – Blood group / Tissue type</td>
<td>20</td>
<td></td>
</tr>
<tr>
<td><strong>Donor-Recipient Relationship</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents</td>
<td>38</td>
<td></td>
</tr>
<tr>
<td>Child (&lt;18)</td>
<td>19</td>
<td></td>
</tr>
<tr>
<td>Child (&gt;18)</td>
<td>19</td>
<td></td>
</tr>
<tr>
<td>Spouses</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>Siblings</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>Child to Parent</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Distant Relatives</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>Friends</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Unspecified</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td><strong>Primary caregiver of recipient</strong></td>
<td></td>
<td>0.757</td>
</tr>
<tr>
<td>Yes</td>
<td>43 (23 M, 20 F)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>51 (29 M, 22 F)</td>
<td></td>
</tr>
<tr>
<td>N/A – Unspecified</td>
<td>5 (4.9%)</td>
<td></td>
</tr>
<tr>
<td>Missing data</td>
<td>1 (1.0%)</td>
<td></td>
</tr>
<tr>
<td><strong>Mean recipient age at donation (years (SD))</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adults</td>
<td>43.3 years (15.09)</td>
<td></td>
</tr>
<tr>
<td>Children</td>
<td>7.6 years (5.0)</td>
<td></td>
</tr>
<tr>
<td><strong>Recipient Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>52</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>43</td>
<td></td>
</tr>
<tr>
<td>Unspecified (therefore recipient gender unknown)</td>
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<td></td>
</tr>
<tr>
<td><strong>Dialysis type</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre-emptive</td>
<td>33</td>
<td></td>
</tr>
<tr>
<td>Haemodialysis</td>
<td>48</td>
<td></td>
</tr>
<tr>
<td>Peritoneal dialysis</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>N/A – Unspecified</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Missing data</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Variable</td>
<td>n / %</td>
<td>P value</td>
</tr>
<tr>
<td>------------------------------</td>
<td>----------------------------</td>
<td>---------</td>
</tr>
<tr>
<td>Years of dialysis</td>
<td></td>
<td>3.8 years (SD 3.15)</td>
</tr>
<tr>
<td>1 – 3 years</td>
<td>35 (57.3%)</td>
<td></td>
</tr>
<tr>
<td>4 – 6 years</td>
<td>16 (26.2%)</td>
<td></td>
</tr>
<tr>
<td>≥7 years</td>
<td>10 (16.4%)</td>
<td></td>
</tr>
<tr>
<td>Previous transplant</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>23</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>70</td>
<td></td>
</tr>
<tr>
<td>N/A – Unspecified</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Number of previous transplants</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>19 (82.6%)</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>4 (17.4%)</td>
<td></td>
</tr>
</tbody>
</table>
Pre-operative questionnaire responses

As discussed in chapter 4 [Methods], the questionnaires consisted of 2 main components: validated psychosocial questionnaires and donation-specific questions which were purposely designed and validated for this study. The validated psychosocial questionnaires are listed in Table 5.4.

Table 5.4: Psychosocial factors, the validated measure selected and the minimum and maximum scores

<table>
<thead>
<tr>
<th>Psychosocial factor</th>
<th>Validated measure selected</th>
<th>Min-Max scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wellbeing</td>
<td>Office of National Statistics Wellbeing questions</td>
<td>0-40</td>
</tr>
<tr>
<td>Distress</td>
<td>General Health Questionnaire 12 (GHQ-12)</td>
<td>0-36</td>
</tr>
<tr>
<td>Depression</td>
<td>Patient Health Questionnaire 2 (PHQ-2)</td>
<td>0-6</td>
</tr>
<tr>
<td>Stress</td>
<td>4 item Perceived Stress Scale (PSS)</td>
<td>0-20</td>
</tr>
<tr>
<td>Health-related Quality of Life</td>
<td>Short Form 12 (Physical components only)</td>
<td>7-31</td>
</tr>
<tr>
<td>Life Satisfaction</td>
<td>Satisfaction with life scale (SWLS)</td>
<td>5-35</td>
</tr>
<tr>
<td>Self-Esteem</td>
<td>Rosenberg</td>
<td>0-30</td>
</tr>
<tr>
<td>Personality</td>
<td>10 item personality inventory (TIPI)</td>
<td>0-20†</td>
</tr>
<tr>
<td>Anxiety</td>
<td>6-item State-Trait Anxiety Inventory (STAI-short)</td>
<td>6-24</td>
</tr>
<tr>
<td>Social support</td>
<td>Multidimensional Scale of Perceived Social Support</td>
<td>12-84</td>
</tr>
<tr>
<td>Optimism</td>
<td>Life Orientation Test - Revised</td>
<td>0-24</td>
</tr>
<tr>
<td>Social comparison</td>
<td>Social Comparison Scale</td>
<td>11-110</td>
</tr>
</tbody>
</table>

†per trait
Psychosocial questionnaires

Table 5.5 outlines the average scores for the pre-operative validated psychosocial questionnaires obtained for the whole sample (mean score provided unless otherwise stated).

<table>
<thead>
<tr>
<th>Validated measures</th>
<th>Pre-operative averages</th>
<th>Sample range</th>
<th>Min-Max scores</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>Score</td>
<td>SD / IQR</td>
</tr>
<tr>
<td>Wellbeing</td>
<td>100</td>
<td>29.51</td>
<td>5.693</td>
</tr>
<tr>
<td>Distress</td>
<td>94</td>
<td>10.22</td>
<td>4.532</td>
</tr>
<tr>
<td>Mood†</td>
<td>100</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Stress</td>
<td>99</td>
<td>4.51</td>
<td>2.708</td>
</tr>
<tr>
<td>SF-12 (Physical)†</td>
<td>99</td>
<td>29</td>
<td>3</td>
</tr>
<tr>
<td>Life Satisfaction†</td>
<td>100</td>
<td>27.5</td>
<td>9</td>
</tr>
<tr>
<td>Self-esteem</td>
<td>98</td>
<td>22.7</td>
<td>4.573</td>
</tr>
<tr>
<td>Anxiety†</td>
<td>96</td>
<td>10</td>
<td>6</td>
</tr>
<tr>
<td>Social Support†</td>
<td>98</td>
<td>72</td>
<td>16</td>
</tr>
<tr>
<td>Optimism</td>
<td>97</td>
<td>21.12</td>
<td>5.885</td>
</tr>
<tr>
<td>Social Comparison</td>
<td>97</td>
<td>68.56</td>
<td>16.181</td>
</tr>
<tr>
<td>Personality†</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Openness</td>
<td>96</td>
<td>11</td>
<td>3</td>
</tr>
<tr>
<td>Conscientiousness</td>
<td>97</td>
<td>12</td>
<td>3</td>
</tr>
<tr>
<td>Extraversion</td>
<td>97</td>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td>Agreeableness</td>
<td>96</td>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td>Emotional stability</td>
<td>98</td>
<td>10</td>
<td>5</td>
</tr>
</tbody>
</table>

† Non-parametric data: Medians and interquartile range provided

Although a control group was not used in this study for reasons outlined in chapter 4, these data can be partially contextualised by analysing them alongside cut-off scores stated by the questionnaire authors or by looking at average scores obtained as part of the questionnaire validation process; most typically from general public or university student samples.

Wellbeing scores indicate that, on average, this sample of living kidney donors have the same level of wellbeing as the general population (LKD sample = 29.5; Office of National Statistics sample = 29.4). The GHQ-12 distress score of 10 is lower than the average score quoted by the authors (average = 11-12). An average mood score of 0 is indicative that the majority of living donors in this sample are not displaying evidence of depression pre-operatively. A stress score of 4.5 in this sample is identical to the
score quoted in a large US population study conducted by the authors of the PSS as part of its development and validation (Cohen, 1983). The physical components of the SF-12 are high (29 out of a possible maximum score of 31), indicating that this sample have a high level of pre-operative physical functioning. This is expected, given the extensive medical screening process that takes place prior to an individual being confirmed as a suitable living kidney donor. Life satisfaction scores were within the average range (23-28) (Pavot and Diener, 1993); indicating that, prior to surgery, this sample of living donors were satisfied with life. Self-esteem scores were also within the normal range (15-25). The optimism score in this sample was 22, which is suggestive of high optimism.

No normal range cut-off scores or average scores from validity testing were available for the STAI-short, the Multidimensional Scale of Perceived Social Support or the Social Comparison Scale. However, for the STAI-short the average score was only 4 points above the minimum possible score; thereby implying that, on average, living donors did not display a large amount of pre-operative state anxiety. The median social support scale score was 72, suggesting a moderate to high level of social support (maximum score = 84). The mean total social comparison score was above the median scale score of 55. This implies that donors see themselves as being above average across the 11 bipolar constructs assessed within the questionnaire.

The “sample range” column of Table 5.5 demonstrates that although the mean and median questionnaire scores were in keeping with average scores or normal ranges, there were some donors who demonstrated evidence of pre-operative psychopathology. Four donors scored 3 or above on the PHQ-2 (≥3 indicates possible low mood) and 1 donor scored above 20 on the GHQ-12 (>20 indicates severe distress). All of these donors had seen a psychologist as a part of their donor workup and had been passed as fit to donate. Further analyses were performed to determine which donor factors may be associated with more negative psychosocial questionnaire scores. These are described in detail below.

*Psychosocial questionnaire scores vs. Demographic data*

Ethnicity was the demographic factor associated with most differences in the psychosocial questionnaire scores. Distress (as measured by the General Health Questionnaire) in white donors (N= 79, M=10.9, SD=4.36) was higher than in non-white donors (N=15, M=6.4, SD=6.47) and was statistically significant (t (92) = -3.74, p<0.001, 95% CI [-6.85, -2.10], d=4.5). Social comparison scores (which demonstrate
how individuals see themselves in relation to others) were lower in white donors (N=80, M=66.45, SD=15.886) when compared to non-white donors (N=17, M=78.47, SD=14.081); which means that white donors saw themselves as having lower social and personal worth than the non-white donors. This was also found to be statistically significant (t (95) = -2.886; p=0.005, 95% CI [-20.290, -3.751], d=-12.021). The personality trait conscientiousness was found to be statistically significantly higher in non-white participants (13.0 (IQR = 1) vs. 12.0 (IQR = 3); U=958.0, p=0.020), however a 1-point difference on a 20-point scale is unlikely to translate into a clinical significance.

Emotional stability was higher in men (12.0 (IQR = 5) vs. 9.0 (IQR= 4); U = 811.50, p=0.008). Age, religious beliefs, level of education, employment status, relationship status and either having children under 18 or adult dependents were not associated with statistically significant differences in any of the psychosocial questionnaire scores. The day, mode and location of questionnaire completion were not associated with any of the psychosocial factors measured.

Pre-operative validated psychosocial questionnaire scores vs. medical, surgical and mental health history

Previous medical or surgical history was not associated with any of the pre-operative validated questionnaire scores. Smokers demonstrated statistically significantly worse mood (1.0 (IQR = 2) vs. 0.5 (IQR = 1); U = 729.0, p=0.04) and lower conscientiousness (10.0 (IQR = 4) vs. 12.0 (IQR = 2); U = 299.50, p=0.008), however these differences were small and were unlikely to translate into a clinically significant difference. Body mass index and blood tests results (C-Reactive Protein (CRP), creatinine and estimated Glomerular Filtration Rate (eGFR)) were not associated with any of the pre-operative questionnaire scores.

Those with a previous history of mental health problems (N=27) were found to have lower pre-operative self-esteem (M = 21.1 (SD = 5.41) vs. M = 23.2 (SD = 4.17); t (95) = 2.06, p=0.042, 95% CI [0.075,4.237], d=2.16), lower emotional stability (8.0 (IQR = 4) vs. 11.5 (IQR = 4); U = 511.50, p<0.001) and lower social support (60.0 (IQR = 19) vs. 72.0 (IQR = 10); U = 604.0, p=0.014). There was no statistically significant difference in any of the validated questionnaire scores between those who had seen a psychologist or psychiatrist pre-operatively as part of their routine living donor workup. Those taking antidepressants at the time of surgery were found to have statistically significantly lower mood, physical health-related quality of life, life satisfaction, self-
esteem, social support, optimism and less emotional stability; however the numbers were small (N=6) so cannot be conclusive.

Pre-operative validated psychosocial questionnaire scores vs. Transplant details and recipient demographics

Donating to a blood or tissue type incompatible recipient was associated with higher distress (12.3 (SD 4.61) vs. 9.7 (SD 4.40); t (92) = -2.18, p=0.032) and higher anxiety (13.5 (IQR=7) vs. 10.0 (IQR=5); U = 1,047.0, p=0.009) when compared to donating to a compatible recipient.

Hypothesis 1.1 stated that those donating to one of their children (parental donors) would be more stressed, anxious and distressed, and would have lower mood, wellbeing and life satisfaction than non-parental donors. Stress and distress was statistically significantly higher in the parental donor group and wellbeing and life satisfaction was statistically significantly lower in the parental donor group (Table 5.6). There was no difference in anxiety and mood between parental donors and non-parental donors. This means that hypothesis 1.1 was partially supported. Interestingly, there was no statistically significant difference in psychological questionnaire scores between parents donating to a child under the age of 18 and parents donating to a child over the age of 18. Anecdotally, donating to a child under 18 has always been associated with being more stressful and distressing to a parent; however it appears that age is irrelevant when the donor is donating to one of their children.

Hypothesis 1.2 stated that those donors who were the primary caregiver to their recipient would be more stressed, anxious and distressed, and would have lower mood, wellbeing and life satisfaction when compared to those who were not a primary caregiver to their recipient. This hypothesis was fully supported (Table 5.7).

Hypothesis 1.3 stated that donors who were donating to a recipient on dialysis would demonstrate more distress when compared to those who were donating to a pre-emptive recipient (someone who was yet to start dialysis). Recipient dialysis status had no effect on any of the pre-operative psychological questionnaire scores and therefore this hypothesis was rejected. It follows that there was also no correlation between pre-operative questionnaire scores and the number of years that the recipient had been on dialysis. There was also no correlation with the recipient having had a previous transplant.
Table 5.6: Validated psychosocial questionnaire scores (Parental vs. Non-parental donors)

<table>
<thead>
<tr>
<th>Pre-operative score</th>
<th>Parental Donor</th>
<th>Non-parental donor</th>
<th>d [95% CI]</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>Score</td>
<td>SD / IQR</td>
<td>N</td>
</tr>
<tr>
<td>Wellbeing</td>
<td>38</td>
<td>27.97</td>
<td>5.543</td>
<td>62</td>
</tr>
<tr>
<td>Distress</td>
<td>37</td>
<td>12.00</td>
<td>4.807</td>
<td>57</td>
</tr>
<tr>
<td>Mood†</td>
<td>38</td>
<td>0</td>
<td>2</td>
<td>62</td>
</tr>
<tr>
<td>Stress</td>
<td>38</td>
<td>5.47</td>
<td>2.379</td>
<td>61</td>
</tr>
<tr>
<td>SF-12 (Physical)†</td>
<td>38</td>
<td>29</td>
<td>4</td>
<td>61</td>
</tr>
<tr>
<td>Life Satisfaction†</td>
<td>38</td>
<td>25.5</td>
<td>11</td>
<td>62</td>
</tr>
<tr>
<td>Self-esteem</td>
<td>36</td>
<td>21.97</td>
<td>4.699</td>
<td>62</td>
</tr>
<tr>
<td>Anxiety†</td>
<td>37</td>
<td>10</td>
<td>6</td>
<td>59</td>
</tr>
<tr>
<td>Social Support†</td>
<td>37</td>
<td>69</td>
<td>17</td>
<td>61</td>
</tr>
<tr>
<td>Optimism</td>
<td>37</td>
<td>20.46</td>
<td>6.044</td>
<td>60</td>
</tr>
<tr>
<td>Social Comparison</td>
<td>37</td>
<td>68.59</td>
<td>14.934</td>
<td>60</td>
</tr>
</tbody>
</table>

* p<0.05
† Non-parametric data: Medians, interquartile range and Mann-Whitney U test statistics presented
Table 5.7: Validated psychosocial questionnaire scores (Primary caregivers vs. non-primary caregivers)

<table>
<thead>
<tr>
<th>Pre-operative score</th>
<th>Primary caregiver</th>
<th>Non-primary caregiver</th>
<th>d [95% CI]</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>Score</td>
<td>SD / IQR</td>
<td>N</td>
</tr>
<tr>
<td>Wellbeing</td>
<td>43</td>
<td>27.21</td>
<td>4.754</td>
<td>57</td>
</tr>
<tr>
<td>Distress</td>
<td>41</td>
<td>12.37</td>
<td>4.403</td>
<td>53</td>
</tr>
<tr>
<td>Mood†</td>
<td>43</td>
<td>0</td>
<td>2</td>
<td>57</td>
</tr>
<tr>
<td>Stress</td>
<td>42</td>
<td>5.48</td>
<td>2.761</td>
<td>57</td>
</tr>
<tr>
<td>SF-12 (Physical) †</td>
<td>39</td>
<td>29</td>
<td>2</td>
<td>54</td>
</tr>
<tr>
<td>Life Satisfaction†</td>
<td>39</td>
<td>24</td>
<td>10</td>
<td>54</td>
</tr>
<tr>
<td>Self-esteem</td>
<td>41</td>
<td>22.05</td>
<td>4.669</td>
<td>57</td>
</tr>
<tr>
<td>Anxiety†</td>
<td>39</td>
<td>12</td>
<td>7</td>
<td>54</td>
</tr>
<tr>
<td>Social Support†</td>
<td>39</td>
<td>72</td>
<td>13</td>
<td>54</td>
</tr>
<tr>
<td>Optimism</td>
<td>42</td>
<td>20.24</td>
<td>6.4</td>
<td>55</td>
</tr>
<tr>
<td>Social Comparison</td>
<td>41</td>
<td>69.17</td>
<td>15.965</td>
<td>56</td>
</tr>
</tbody>
</table>

* p<0.05
† Non-parametric data: Medians, interquartile range and Mann-Whitney U test statistics presented
Donation-specific questions

The responses given to each of the pre-operative donation specific questions are displayed below. The responses are divided into the following categories: The donation process, Thoughts about donation, The recipient, Markers of altruistic behaviour, Expectations and Attitudes towards donation. Statistical analyses were conducted to determine whether any of the answers given were associated with demographic factors, previous medical, surgical and mental health history or any transplant and recipient factors. The donation-specific questions were also analysed against the psychosocial measures.

The donation process

“How long ago did you first consider being a Living Kidney Donor?” (Figure 5.1)

For the majority of donors the decision to become a living donor was made more than 12 months prior to the donation going ahead (62%). Deciding to donate more than 12 months previously was associated with lower pre-operative stress ($t(91) = 2.322; p=0.022$, 95% CI [0.316, 4.064], $d=2.19$).

![Figure 5.1: “How long ago did you first consider being a Living Kidney Donor?”](image-url)
“How long did it take for you to donate? (From initial discussion with a transplant coordinator to your operation)” (Figure 5.2).

The donation process most commonly took between 6 and 12 months (38%)

**Figure 5.2: “How long did it take for you to donate?”**

**Decision making**

The majority of donors stated that they made their decision to donate instantly (Figure 5.3), with 78% agreeing or strongly agreeing with the statement. An instant decision to become a donor was strongly associated with being a parent donating to a child: 97.4% of parental donors stated that they made the decision to donate instantly vs. 71.9% of non-parent donors ($\chi^2 (1, N=95) = 10.042, p=0.002$).

**Figure 5.3: “When Living Donation was first mentioned I knew instantly that I would be prepared to donate”**
Did the donor offer or were they asked to donate? (Figure 5.4)

Most donors offered to donate their kidney (87%). There was a statistically significant association between being donating to an incompatible recipient and being asked to donate, (Fishers exact test \((1, N=93) = 14.524, p=0.002\)).

![Bar chart showing the distribution of donors who offered, asked, unspecified, and missing.

Figure 5.4: Did the donor offer or were they asked to donate?

Hypothesis 1.4 stated that those who were asked to donate would demonstrate increased pre-operative stress, anxiety and distress. There were no significant differences in any of the psychosocial questionnaire scores between those who offered and those who were asked to donate, so therefore hypothesis 1.4 was rejected.

Other possible donors

Hypothesis 1.5 stated that those donors who were the only available donor for their recipient would demonstrate increased pre-operative stress, anxiety and distress. Therefore donors were asked how many others (excluding themselves) had offered to donate a kidney to the intended recipient (Figure 5.5) and how many others had been for tests and had been found suitable (Figure 5.6). In 19% of cases, the donor was the only person who had offered to donate and 63% were found to be the only suitable donor for their intended recipient. Having other offers or alternative available donors was not associated with any demographic, transplant or recipient data, nor any of the pre-operative scores obtained for the validated questionnaires. Hypothesis 1.5 was therefore rejected.
Figure 5.5: “How many other people (excluding you) offered to donate a kidney to your recipient?”

Figure 5.6: “How many other people (excluding you) went for tests AND were suitable to donate?”

Thoughts about donation
Donors were asked how often they thought about their decision to become a living donor (Figure 5.7), the process of donation, such as the pre-operative work up, the operation, hospital stay and the post-operative recovery (Figure 5.8), and the impact of donation on their social circumstances, such as work, money and housing (Figure 5.9).

The majority had thought about their decision to donate a few times per week (34%). There was a small, statistically significant correlation between frequency of thoughts about the decision to donate and anxiety ($r (94) = 0.263; p=0.010$). Most donors thought about the process of donation a few times per week (36%) and their social circumstances a few times a month (35%).
Figure 5.7: “Since you first agreed or decided to donate how often have you thought about it?”

Figure 5.8: “Since deciding to be a Living Kidney Donor, how often have you thought about the process you will have to go through?”

Figure 5.9: “Since deciding to be a Living Kidney Donor, how often have you thought about your social circumstances and how these may be affected by donating?”
Thinking about the process of donation more than once per week was more common in primary caregivers (79.1% vs. 50.9%; $\chi^2 (1, N=100) = 8.357, p=0.007; OR = 3.6$) and in those donating to an incompatible recipient (85.0% vs. 57.5%; $\chi^2 (1, N=100) = 5.191, p=0.043; OR = 4.2$). Thinking about the process of donation more frequently correlated significantly with lower wellbeing and higher distress, stress and anxiety (Table 5.8).

Table 5.8: Correlations between time spent thinking about the process of donation and wellbeing, distress, stress and anxiety (Spearman correlation)

<table>
<thead>
<tr>
<th>Time spent thinking about the process of donation</th>
<th>Wellbeing</th>
<th>Distress</th>
<th>Stress</th>
<th>Anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td>Correlation Coefficient</td>
<td>-0.230</td>
<td>0.265</td>
<td>0.217</td>
<td>0.352</td>
</tr>
<tr>
<td>Sig (2-tailed)</td>
<td><strong>0.021</strong>*</td>
<td><strong>0.010</strong>*</td>
<td><strong>0.031</strong>*</td>
<td>&lt;0.001***</td>
</tr>
<tr>
<td>N</td>
<td>100</td>
<td>94</td>
<td>99</td>
<td>96</td>
</tr>
</tbody>
</table>

* $p<0.05$

Thinking about the social aspects of living donation more than once per week was significantly higher in primary caregivers (65.1% vs. 38.6%; $\chi^2 (1, N=100) = 6.895, p=0.015; OR = 3.0$). It was also associated with higher distress, anxiety and lower mood (Table 5.9).

Table 5.9: Correlations between time spent thinking about the social aspects of donation and distress, anxiety and mood

<table>
<thead>
<tr>
<th>Time spent thinking about the social circumstances of donation</th>
<th>Distress</th>
<th>Anxiety</th>
<th>Mood</th>
</tr>
</thead>
<tbody>
<tr>
<td>Correlation Coefficient</td>
<td>0.265</td>
<td>0.272</td>
<td>0.241</td>
</tr>
<tr>
<td>Sig (2-tailed)</td>
<td><strong>0.010</strong>*</td>
<td><strong>0.007</strong>*</td>
<td><strong>0.016</strong>*</td>
</tr>
<tr>
<td>N</td>
<td>94</td>
<td>96</td>
<td>100</td>
</tr>
</tbody>
</table>

* $p<0.05$

The recipient
The majority of donors believed their recipient to be either unwell (39%) or extremely unwell (23%) at the time they made the decision to donate (Figure 5.10). Donor perceptions of their recipient’s health at the time of donation were not associated with any demographic, transplant or recipient data, nor any of the pre-operative scores obtained for the validated questionnaires.
Donors frequently worried about their recipient and the possibility of the transplant failing (Figure 5.11).

Worrying more than once per week about the recipient or the transplant failing was significantly associated with donating to an incompatible recipient (90.0% incompatible recipient vs. 54.7% compatible recipient; \( \chi^2 (1, N=95) = 8.632, p=0.007; \) OR = 1.7) and donating to someone on dialysis (70.5% recipient on dialysis vs. 45.5% recipient not on dialysis; \( \chi^2 (1, N=94) = 5.681, p=0.031; \) OR = 2.9). Time spent worrying about the recipient correlated positively with distress, anxiety and mood (Table 5.10).
Table 5.10: Correlations between time spent worrying about the recipient and wellbeing, distress, anxiety and mood

<table>
<thead>
<tr>
<th>Worrying about the recipient</th>
<th>Distress</th>
<th>Anxiety</th>
<th>Mood</th>
</tr>
</thead>
<tbody>
<tr>
<td>Correlation Coefficient</td>
<td>0.257</td>
<td>0.458</td>
<td>0.315</td>
</tr>
<tr>
<td>Sig (2-tailed)</td>
<td><strong>0.015</strong>*</td>
<td>&lt;0.001*</td>
<td>0.002*</td>
</tr>
<tr>
<td>N</td>
<td>89</td>
<td>91</td>
<td>95</td>
</tr>
</tbody>
</table>

*p<0.05

Markers of altruistic behaviour (Figure 5.12)

Blood donation was significantly higher in unspecified donors (80.0% vs. 23.2%; $\chi^2 (1, N=100) = 7.977, p=0.021; OR = 13.3$), in those who had attended higher education (33.8% vs. 10.7%; $\chi^2 (1, N=96) = 5.363, p=0.039; OR = 4.2$) and in non-primary caregivers (35.1% vs. 14.0%; $\chi^2 (1, N=100) = 5.690, p=0.031; OR = 6.2$). Registration on the organ donor register was higher in unspecified donors (100% vs. 46.3%; Fisher’s exact test; $p=0.035$), in white donors (57.3% vs. 11.1%; $\chi^2 (2, N=100) = 13.606, p=0.001; OR = 11.8$) and in those who had attended higher education (58.8% vs. 25.0%; $\chi^2 (2, N=96) = 9.249, p=0.008; OR = 4.1$).

Figure 5.12: Markers of altruistic behaviour
Expectations of life after living donation and transplantation

Donors were asked whether they expected the day-to-day lives of their recipient, themselves and those around them to improve after donation ("After the transplant my recipient’s day-to-day life/ my own day-to-day life / the day-to-day life of those around me will get better") (Figure 5.13). Donors were also asked for their level of agreement for the following question regarding personal benefit: “How much I benefit from my donation will depend very much on how well my recipient does” (Figure 5.14).

![Figure 5.13: Expectations after living donation and transplantation](image)

![Figure 5.14: “How much I benefit from my donation will depend very much on how well my recipient does”](image)
Ninety-one percent of donors agreed or strongly agreed with the statement "After the transplant my recipient’s day-to-day life will get better”. Forty-five percent agreed or strongly agreed with the statement “After the transplant my own day-to-day life will get better”. Fifty-two percent agreed or strongly agreed with the statement “After the transplant the day-to-day lives of those around me will get better”. The majority of donors anticipated that their personal gain from donation would depend very much on how well their recipient did after their transplant (77%).

Expectations of an improvement in their own quality of life after donation were significantly higher in spousal donors: 71.4% of spousal donors agreed or strongly agreed with the statement vs. 40.6% non-spousal donors ($\chi^2 (1, N=95) = 12.629, p=0.015; OR = 3.7$). Expectations of an improvement in the quality of life of those around them were significantly higher in those donating to a parent (83.3% vs. 52.8%; $\chi^2 (4, N=95) = 10.248, p=0.018; OR = 4.5$), primary caregivers (69.8% vs. 42.3%; $\chi^2 (4, N=95) = 9.968, p=0.028; OR = 3.2$) and in non-white donors (72.2% vs. 50.7%; $\chi^2 (4, N=95) = 12.200, p=0.026; OR = 2.5$). There was no correlation between level of agreement with these question and any of the pre-operative psychosocial questionnaire scores.

Collectively these results unsurprisingly show that donors viewed their recipient as the main beneficiary of their donation. This was followed by others within their social network and then themselves. It follows that the majority of donors also felt that how much they would get out of their donation was heavily dependent on how well or unwell their recipient was after the transplant had taken place. One may conclude from these results that donors’ expectations of life after the transplant lie predominantly with the recipient and their health following transplantation. Their views on how successful the transplant has been are therefore also likely to rest on the recipient’s outcome. This justifies hypotheses 3.2.2 - 3.2.4 which state that donor psychosocial outcomes may demonstrate a decline in circumstances where recipients experience post-operative complication, graft loss and / or death, or where the donor’s relationship with their recipient deteriorates after donation.

**Attitudes towards donation**

In terms of donors’ attitudes towards living donation, 96% felt that organ donation was a good thing to do and 91% felt good about being a kidney donor (agreed or strongly agreed with the statement). 87% felt supported by those closest to them (Figure 5.15). Agreement with the statement “I think organ donation (in general) is a good thing” was
higher for white donors (96.3% vs. 94.4; $\chi^2 (3, N=100) = 10.513, p=0.024; \text{OR} = 1.5$) and in those donating to a recipient who had previously received a transplant (100% vs. 94.3%; $\chi^2 (3, N=93) = 7.935, p=0.047$).

Summary of findings from Section 1

This section of data analysis corresponds to the first hypothesis of the study: that there would be a number of donor and transplant-related factors associated with poorer than average psychosocial questionnaire scores pre-operatively. These 5 factors included: being a parental donor, being a primary caregiver to the recipient, donors whose recipients were on dialysis, donors who were asked to donate and donors who were the only available donor for their recipient.

Hypotheses 1.1 and 1.2 stated that parental donors and donors who were primary caregivers would be more stressed, anxious and distressed, and would have lower mood, wellbeing and life satisfaction before donation. In both groups, pre-operative stress and distress was statistically significantly higher and pre-operative wellbeing and life satisfaction was statistically significantly lower. There were no statistically significant differences in anxiety or mood in the parental donor group, however these were both significantly worse in the primary caregiver group. Hypothesis 1.1 was therefore partially supported and hypothesis 1.2 was fully supported.
Hypotheses 1.3, 1.4 and 1.5, related to recipient dialysis status, being asked by the recipient to donate and being the only potential donor, were all rejected as none of these factors were associated with worse distress, stress or anxiety. An unexpected finding was that distress and anxiety were found to be higher in those donating to an incompatible recipient when compared to those donating to a compatible recipient. These donors were also more likely to be asked to donate, rather than offer. Pre-operatively, the majority of donors anticipated that the benefit to themselves would be through their recipient; that is, how much they got out of the process of donation would be closely related to how the recipient did after transplantation.

An important finding in this section was related to the mental health assessment conducted as part of the living donor workup. 27% of donors recruited to the study had a current or previous history of mental health illness. A significant proportion of these (7 donors; 25.9%) received no mental health review as part of their living donor workup, despite this being a recommendation in the British Transplantation Society guidelines. Those with a previous history of mental health problems were found to have lower pre-operative self-esteem, emotional stability and social support.

Demographic factors that were associated with differences in the psychosocial questionnaire scores included ethnicity and gender. Distress was found to be 4.5 points higher in white versus non-white donors. Social comparison scores were 12 points lower in white donors, which meant that white donors saw themselves as having lower social and personal worth than non-white donors. Men were found to have higher emotional stability than women. No other demographic factors were of statistical significance.

Other findings of interest included the markers of altruistic behaviour and where donors expected the benefits of living donation to be. Those markers of altruistic behaviour that were related to healthcare demonstrated that 49% were signed up to the organ donor register, which is higher than the UK average of 31% (NHS Blood and Transplant, 2013). The numbers on the bone marrow register were also higher than the UK average (9% vs. 1.5%) (NHS Blood and Transplant, 2013), as were the numbers who regularly donated blood (26% vs. 4%) (NHS Blood and Transplant, 2014).
Section 2: Post-operative data

Post-operative complications

Three Months

Of the 93 study participants who went on to donate, 82 completed a questionnaire at 3 months (11.8% dropout rate). The majority were completed at home (81 questionnaires (98.8%)) and online (57 questionnaires (69.5%)), rather than on paper. The 3 month questionnaire was completed, on average, 97 days after donation (IQR=14). As was the case pre-operatively, all questionnaires were self-completed.

Table 5.11 provides self-reported details of donor complications and recovery as documented on the 3 month questionnaire (N=82). 13 donors were readmitted to hospital due to post-operative complications (severe pain (3), infection of unknown origin (3), intra-abdominal collection (2), pneumothorax (1), ileus due to intra-abdominal infection (1), infected seroma (1), abdominal pain (1), wound infection (1), appendicitis (1)). One donor was admitted on two separate occasions for different reasons. Five donors returned to the operating theatre for a second operation to treat a complication: 4 for a laparoscopic washout of abdomen (performed for abdominal pain, or suspected or proven intra-abdominal collections) and 1 for an appendicectomy.

The median length of hospital stay (LOS) for the whole sample was 4 days (IQR 2 days) (Range = 2-7 days), where day 1 corresponds to the first post-operative day (the day after surgery). LOS was not significantly associated with the presence of complications (U=734.5; p=0.953), the readmission rate to hospital (U=168.5; p=0.695) or the reoperation rate (U=67.5; p=0.529). LOS was statistically significantly higher in women (U=1423.0; p=0.005). No other demographic factors were associated with LOS (age, ethnicity, level of education, employment status or relationship status).

Donor-recipient relationship, primary caregiver status and previous medical, surgical or mental health history were also not associated with LOS. There was a small negative correlation between LOS and pre-operative life satisfaction scores (r (91) = -0.207; p=0.047), pre-operative emotional stability (r (89) = -0.219; p=0.037) and pre-operative optimism (r (88) = -0.266; p=0.011).
Table 5.11: 3 month donor complications (self-report)

<table>
<thead>
<tr>
<th>Complications – details*</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Post-operative complications</td>
<td>37</td>
<td>39.8</td>
</tr>
<tr>
<td>Severe pain</td>
<td>10</td>
<td>12.2</td>
</tr>
<tr>
<td>Wound infection</td>
<td>8</td>
<td>9.8</td>
</tr>
<tr>
<td>Urine infection</td>
<td>6</td>
<td>7.3</td>
</tr>
<tr>
<td>Infection of unknown origin</td>
<td>5</td>
<td>6.1</td>
</tr>
<tr>
<td>Intra-abdominal collection</td>
<td>4</td>
<td>4.9</td>
</tr>
<tr>
<td>Swollen testicle</td>
<td>3</td>
<td>3.7</td>
</tr>
<tr>
<td>Chest infection</td>
<td>3</td>
<td>3.7</td>
</tr>
<tr>
<td>Seroma</td>
<td>3</td>
<td>3.7</td>
</tr>
<tr>
<td>Viral infection</td>
<td>1</td>
<td>1.2</td>
</tr>
<tr>
<td>Pneumothorax</td>
<td>1</td>
<td>1.2</td>
</tr>
<tr>
<td>Vasovagal syncope</td>
<td>1</td>
<td>1.2</td>
</tr>
<tr>
<td>Ileus</td>
<td>1</td>
<td>1.2</td>
</tr>
<tr>
<td>Abdominal pain</td>
<td>1</td>
<td>1.2</td>
</tr>
<tr>
<td>Appendicitis</td>
<td>1</td>
<td>1.2</td>
</tr>
<tr>
<td>Leg cramp</td>
<td>1</td>
<td>1.2</td>
</tr>
<tr>
<td>Readmission to hospital</td>
<td>13</td>
<td>15.9</td>
</tr>
<tr>
<td>(Guy’s or local hospital)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reoperation</td>
<td>5</td>
<td>7.9</td>
</tr>
<tr>
<td>Return to driving</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does not drive</td>
<td>10</td>
<td>10.8</td>
</tr>
<tr>
<td>Less than 4 weeks</td>
<td>17</td>
<td>18.3</td>
</tr>
<tr>
<td>4-6w</td>
<td>34</td>
<td>36.6†</td>
</tr>
<tr>
<td>6-12w</td>
<td>16</td>
<td>17.2</td>
</tr>
<tr>
<td>More than 12 weeks</td>
<td>4</td>
<td>4.3</td>
</tr>
<tr>
<td>Missing data</td>
<td>12</td>
<td>12.9</td>
</tr>
<tr>
<td>Return to work</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not working at present</td>
<td>12</td>
<td>12.9</td>
</tr>
<tr>
<td>Less than 4 weeks</td>
<td>11</td>
<td>11.8</td>
</tr>
<tr>
<td>4-6 weeks</td>
<td>14</td>
<td>15.1</td>
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<tr>
<td>6-12 weeks</td>
<td>33</td>
<td>35.5†</td>
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<tr>
<td>More than 12 weeks</td>
<td>9</td>
<td>9.7</td>
</tr>
<tr>
<td>Missing data</td>
<td>14</td>
<td>15.1</td>
</tr>
<tr>
<td>Return to normal (mean)</td>
<td>7.8 weeks (SD 3.30)</td>
<td></td>
</tr>
<tr>
<td>“I do not feel back to normal yet”</td>
<td>31</td>
<td>33.33</td>
</tr>
<tr>
<td>Residual wound pain (median)</td>
<td>1 (IQR: 2)</td>
<td></td>
</tr>
</tbody>
</table>

* The number of complications listed is >37 due to some donors having more than 1 complication after their surgery
† Modal answer
The majority of donors returned to driving 4-6 weeks after surgery. Returning to driving after 6 weeks was not associated with having had a post-operative complication ($\chi^2 = (4, N=76) = 2.01, p=0.735$), however was associated with being readmitted to hospital ($\chi^2 = (4, N=72) = 11.02, p=0.026$) and requiring an operation for complications ($\chi^2 = (4, N=73) = 17.77, p=0.001$). The majority of donors returned to work 6-12 weeks after surgery. Returning to work before or after this time was not associated with having had a complication ($\chi^2 = (4, N=75) = 2.78, p=0.595$), being readmitted to hospital ($\chi^2 = (4, N=71) = 0.73, p=0.948$) or needing a further operation ($\chi^2 = (4, N=72) = 2.01, p=0.734$). The time taken to return to driving and work was not associated with any pre-operative psychological questionnaire scores.

By 3 months, 31 donors reported not feeling back to their normal self (37.8%). Feeling back to normal by 3 months was not associated with having had a complication ($\chi^2 = (1, N=77) = 0.945, p=0.331$), being readmitted to hospital ($\chi^2 = (1, N=73) = 0.273, p=0.601$) or requiring a second operation ($\chi^2 = (1, N=74) = 0.029, p=0.866$). Feeling back to normal by 3 months was also not associated with any demographic factors (gender, age, ethnicity, level of education, employment status or relationship status), primary caregiver status, donor-recipient relationship, nor previous medical, surgical or mental health history.

Not feeling back to normal by 3 months was associated with statistically significant differences in some of the pre-operative psychological questionnaire scores. For the purposes of this analysis those feeling back to normal by 3 months will be referred to as group 1 and those not feeling back to normal by 3 months will be referred to as group 2.

Pre-operative wellbeing in group 1 ($N = 50, M=30.58, SD=5.119$) was found to be higher than group 2 ($N=31, M=27.65, SD=6.275$) ($t (79) = -2.298; p=0.024; 95\% \text{ CI } [-5.477, -0.393], d = -2.935$). Pre-operative stress in group 1 ($N=49, M=4.22, SD=2.409$) was lower than in group 2 ($N=31, M=5.48, SD=2.803$) ($t (78) = 2.137; p=0.036, 95\% \text{ CI } [0.086, 2.433], d = 1.259$). Donors in group 2 scored worse across 10 of the 11 questionnaires at 3 months (Table 5.12). For those donors in group 1 there was no correlation between the number of weeks taken to feel back to normal and any of the 3 month validated questionnaire scores.
Table 5.12: 3 month questionnaire scores in those who reported feeling back to normal by 3 months and those who did not feel back to normal by 3 months

<table>
<thead>
<tr>
<th>3 month questionnaire score</th>
<th>Back to normal by 3 months (Group 1)</th>
<th>Not back to normal by 3 months (Group 2)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>Score</td>
<td>SD / IQR</td>
</tr>
<tr>
<td>Wellbeing</td>
<td>48</td>
<td>30.94</td>
<td>4.679</td>
</tr>
<tr>
<td>Distress</td>
<td>48</td>
<td>7.40</td>
<td>3.113</td>
</tr>
<tr>
<td>Mood†</td>
<td>41</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Stress</td>
<td>50</td>
<td>3.54</td>
<td>2.501</td>
</tr>
<tr>
<td>SF-12 (Physical)†</td>
<td>41</td>
<td>28.0</td>
<td>3</td>
</tr>
<tr>
<td>Life Satisfaction†</td>
<td>41</td>
<td>28.0</td>
<td>6</td>
</tr>
<tr>
<td>Self-esteem</td>
<td>47</td>
<td>22.79</td>
<td>4.653</td>
</tr>
<tr>
<td>Anxiety†</td>
<td>41</td>
<td>8.0</td>
<td>5</td>
</tr>
<tr>
<td>Social Support†</td>
<td>41</td>
<td>72.0</td>
<td>9</td>
</tr>
<tr>
<td>Optimism</td>
<td>49</td>
<td>22.20</td>
<td>5.397</td>
</tr>
<tr>
<td>Social Comparison</td>
<td>50</td>
<td>70.70</td>
<td>15.149</td>
</tr>
</tbody>
</table>

* p<0.05
† Non-parametric data: Medians, interquartile range and Mann-Whitney U test statistics presented

Analysis of Covariance (ANCOVA) tests were performed to determine whether the statistically significant differences in 3 month psychosocial questionnaire scores between the two groups remained once the pre-operative score was controlled for. Only 4 questionnaires (wellbeing, distress, stress and anxiety) met the assumptions necessary for accurate interpretation of the ANCOVA results (Table 5.13). The 3 month questionnaire scores for each of these psychosocial factors remained statistically significant between the 2 groups once the pre-operative questionnaire score had been controlled for.
Table 5.13: 3 month questionnaire scores in those who reported feeling back to normal by 3 months and those who did not feel back to normal by 3 months (adjusted and unadjusted scores)

<table>
<thead>
<tr>
<th>3 month questionnaire score</th>
<th>Back to normal by 3 months (Group 1)</th>
<th>Not back to normal by 3 months (Group 2)</th>
<th>Unadjusted mean difference</th>
<th>Adjusted mean difference*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>Score</td>
<td>SD / IQR</td>
<td>n</td>
</tr>
<tr>
<td>Wellbeing</td>
<td>48</td>
<td>30.94</td>
<td>4.679</td>
<td>31</td>
</tr>
<tr>
<td>Distress</td>
<td>48</td>
<td>7.4</td>
<td>3.113</td>
<td>29</td>
</tr>
<tr>
<td>Stress</td>
<td>50</td>
<td>3.54</td>
<td>2.501</td>
<td>31</td>
</tr>
<tr>
<td>Anxiety</td>
<td>41</td>
<td>8</td>
<td>5</td>
<td>21</td>
</tr>
</tbody>
</table>

*p<0.05

* adjusted for pre-operative questionnaire score
Those donors who felt back to normal by 3 months (n=51) did so on average 7.8 weeks after surgery ($SD = 3.30$; range = 1-16 weeks). The number of weeks taken to return to normal in primary caregivers was 9.1 weeks ($SD = 3.43$) and in non-primary caregivers was 6.8 weeks ($SD=2.90$) ($t (48) = -2.52; p=0.015$).

The median residual wound pain score at 3 months was 1 (IQR=2; range = 0-10). The 3 month wound pain score did not correlate with any demographic factors, complications, readmission to hospital or requiring a further operation, nor any of the pre-operative psychosocial questionnaire scores.

Twenty-three recipients (26.1%) were reported to have had complications after their transplant, with 3 (6.7%) requiring at least one session of dialysis post-operatively. Recipient complications included: infection (7), rejection (6), reoperation (5), thrombosis (3), gastrointestinal complications (2), urological complications (2), post-operative bleeding (1) and myocardial infarction (1). Donors also reported other minor issues (8) which included side effects of medications, blood pressure control and seizures. One recipient had their transplant kidney explanted due to severe acute antibody mediated rejection. Complication rates were not higher in those who had received an incompatible transplant ($\chi^2 = (1, N=76) = 0.008; p=0.931$). The analysis of 3 month donor and recipient complications against post-operative psychosocial questionnaire responses is found in section 3 (sub-analysis).

**Twelve months**

The 12 month questionnaire was completed by 77 donors (17.2% total dropout rate). The majority of questionnaires were completed at home (72 questionnaires; 93.5%) and online (50 questionnaires; 64.9%). The 12 month questionnaire was completed, on average, 367.0 days after donation (IQR=9). All questionnaires were self-completed.

Donors were asked whether they had acquired any new medical or surgical problems related to their donor operation since they completed the questionnaire at 3 months. 12 donors stated that they had, with some listing more than one problem. These included: recurrent urinary infections (5), severe pain (location not provided) (2), tiredness (1), hip pain (1), incisional hernia (1), testicular pain (1), hypertension (1), hypothyroidism (1) and gynaecological issues (details not provided) (1). Of these 12 donors, 2 had required more than one further admission since they donated. Both donors were female and had been admitted with urine infections. The median wound
pain score at 12 months was 0 (IQR=1; range = 0-6). The mean creatinine at 12 months was 113.4 umol/L (SD 22.167) and the mean eGFR was 55.8 mL/min (SD 10.537). There was no statistically significant correlation between either of these blood tests and 12 month psychosocial questionnaire scores.

Sixty-five donors (80.2%) felt that they had returned to their normal selves by 12 months. Of the 9 donors who did not feel back to normal by 12 months, 7 had not felt back to normal by 3 months and 2 contradicted the answer they had previously given on their 3 month questionnaire. Not feeling back to normal by 12 months was not associated with having experienced a complication related to surgery, nor a further admission to hospital. Not feeling back to normal was associated with significantly worse scores for wellbeing, distress, stress, self-esteem, social comparison, mood and physical health related quality of life; however the numbers were small (N=9) so cannot be conclusive.

A further 15 recipients (17.0%) developed complications after their transplant. New complications, occurring in recipients with and without complications at 3 months, included: severe infections (10), urological complications (incl. recurrent infections) (6), rejection (3), further surgical procedures (hernia repair, native nephrectomy, amputation) (4), bowel cancer (1), neurological complications (stroke with aphasia and paralysis, seizures, Transient-Ischaemic Attacks (3), severe pain (1), CMV viraemia (1), hypertension (1), deranged renal function (unknown cause) (1), electrolyte abnormalities (1), Diabetes Insipidus (1), lymphocele (1), recurrence of primary disease (1) and osteopenia (1).

All recipients of those donors responding to the 12 month questionnaire were alive at 12 months, however 1 recipient is known to have died within the first 3 months of donation. Neither the 3 month, nor the 12 month questionnaires were returned by the corresponding donor. A second recipient had lost their graft by 12 months due to recurrence of the primary disease and episodes of rejection. Therefore, the total graft loss for the study sample by 12 months was 2 and there had been 1 death.

The analysis of 12 month donor and recipient complications against post-operative psychosocial questionnaire responses is found in section 3 (sub-analysis).
Documented post-operative psychological issues

Of the 93 participants who went on to donate, 5 (5.4%) had post-operative psychological issues documented in their medical notes. Three donors were male and 2 were female. Four donors donated to one of their own children (3 paediatric recipients, 1 adult recipient) and 1 donated to a spouse. Documented psychological issues included: low mood (2 donors), increased anxiety related to the recipient's health (2 donors), increased anxiety when attending the hospital (1 donor; recipient deceased), feelings of guilt (2 donors), difficulty coping (1 donor) and anger management issues (1 donor).

Six donors (6.5%) were offered a referral to a clinical psychologist. Four had reported psychological issues to the clinical team as noted above and an additional 2 donors were referred following disclosure that their relationship with their recipient had deteriorated after the transplant. Of these 6 donors, 2 were seen by a psychologist (1 female, 1 male), 3 were made appointments but did not attend (1 female, 2 male) and 1 male donor declined the offer.

Of the 2 donors who were seen by a clinical psychologist, 1 was diagnosed with moderate depression and severe anxiety following completion of 2 validated depression and anxiety measures as part of the consultation. This was 18 months after she had donated to one of her own children who was aged under 18; the youngest of her 3 children. Of note, the depression scores obtained as part of the study demonstrated an improvement at 12 months when compared to pre-operative scores (PHQ-2 score changed from 2 to 1), whereas the 12 month anxiety score had increased (STAI-short score changed from 14 to 16). A mental health history had been taken by the living donor co-ordinator, nephrologist and transplant surgeon who had seen the donor in the clinic before she donated, however her current mental health status had not been elicited. This donor had a background of depression but was not receiving any treatment at the time of donation. A pre-operative referral to psychological services was therefore not made.

In the post-operative psychological consultation the donor discussed how she had struggled to manage with the long-term knowledge that the transplant would not last forever. This donor felt guilty towards the recipient, blaming herself for her child’s illness. She was struggling to enjoy life, despite expecting things to improve once the transplant had taken place. A reduction in social support from her family, the hospital and respite services left her struggling to cope and she felt poorly supported.
emotionally by her spouse, family and friends. Despite making a follow up appointment with psychological services this donor failed to attend her appointments and was therefore discharged from the service.

The second donor seen by a psychologist was referred 6 months after donation for anxiety towards his recipient's health and difficulty coping. His recipient was his spouse, who had 2 children from a previous relationship. He did not complete any validated questionnaires as part of his consultation, however his state-trait anxiety score given for the study was found to be increased at both 3 and 12 months when compared to pre-operative scores. This donor was not formally asked about his mental health history or his current mental state by any of the transplant team who saw him as part of his workup. He disclosed a history of low mood to the research team and was not receiving any treatment at the time of donation.

In the post-operative psychological consultation this donor discussed how he and his family had experienced financial difficulties at the time of donation; both due to redundancy and the need for him to become his recipient's primary caregiver, which had left him unable to work. He felt poorly supported by his family and social services. Additionally, this donor had witnessed his recipient (his wife) have a cardiac arrest in the early days after her diagnosis of renal failure had been made. He had found this very traumatic and spent the months and years after this event being “paranoid” that she would die in her sleep. He would lie next to her in bed at night and at times would feel the need to wake her up in order to check that she was still alive. Anxiety towards his recipient’s health continued after the transplant and this was exacerbated by an early episode of acute rejection.

This donor did not make any further appointments to see the psychology team but reported to the research team a few months later that he and his recipient had separated. He stated that their separation had been initiated by the recipient and he remained unsure of what had prompted her to ask him to leave. By 12 months neither party were speaking to one another. The donor claimed that he had not been allowed to see his recipient’s children who he had previously brought up as his own.
**Non-responders**

Of the 16 participants failing to complete all 3 questionnaires, 8 completed no follow up questionnaires at all (8.6%), 8 completed a questionnaire at 3 months only (8.6%) and 3 completed a questionnaire at 12 months only (3.2%).

Demographic factors were analysed alongside questionnaire completion rates (Table 5.14). The only demographic variable that was associated with follow up questionnaire completion was ethnicity, with non-white participants less likely to complete a follow up questionnaire (73 white vs. 9 non-white). There was no statistically significant difference in pre-operative validated questionnaire scores between those who did and did not respond to the 3 and 12 months questionnaires.

**Table 5.14: Demographic details vs. Questionnaire completion rates at 3 and 12 months**

<table>
<thead>
<tr>
<th></th>
<th>3 months</th>
<th></th>
<th></th>
<th>12 months</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Completed</td>
<td>Not completed</td>
<td>p</td>
<td>Completed</td>
<td>Not completed</td>
<td>p</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Male</td>
<td>42</td>
<td>9</td>
<td>0.056</td>
<td>39</td>
<td>12</td>
<td>0.075</td>
</tr>
<tr>
<td>Female</td>
<td>40</td>
<td>2</td>
<td></td>
<td>38</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Age (years) (Mean)</td>
<td>45.6</td>
<td>38.5</td>
<td>0.083</td>
<td>45.9</td>
<td>39.1</td>
<td>0.05</td>
</tr>
<tr>
<td>Ethnicity</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>White</td>
<td>73</td>
<td>3</td>
<td>&lt;0.001</td>
<td>66</td>
<td>10</td>
<td>0.029*</td>
</tr>
<tr>
<td>Non-white</td>
<td>9</td>
<td>8</td>
<td></td>
<td>11</td>
<td>6</td>
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</tr>
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<td>Religious beliefs</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>48</td>
<td>8</td>
<td>0.246</td>
<td>47</td>
<td>9</td>
<td>0.623</td>
</tr>
<tr>
<td>No</td>
<td>32</td>
<td>2</td>
<td></td>
<td>27</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Education</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>None/School leaver</td>
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<td>2</td>
<td>0.349</td>
<td>21</td>
<td>6</td>
<td>0.372</td>
</tr>
<tr>
<td>College / Higher</td>
<td>53</td>
<td>9</td>
<td></td>
<td>53</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Employment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not working / retired</td>
<td>12</td>
<td>3</td>
<td>0.119</td>
<td>13</td>
<td>2</td>
<td>0.434</td>
</tr>
<tr>
<td>Working</td>
<td>69</td>
<td>7</td>
<td></td>
<td>63</td>
<td>13</td>
<td></td>
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<tr>
<td>Relationship status</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single/Divorced</td>
<td>25</td>
<td>3</td>
<td>0.808</td>
<td>22</td>
<td>6</td>
<td>0.379</td>
</tr>
<tr>
<td>Married/Partner</td>
<td>56</td>
<td>8</td>
<td></td>
<td>55</td>
<td>9</td>
<td></td>
</tr>
</tbody>
</table>

* p<0.05
The Electronic Patient Record (EPR) was interrogated alongside researcher notes in an attempt to recognise whether there were any potential explanations for why donors did not return a post-operative questionnaire. In the majority of cases, no clear cause could be ascertained. Eighty-seven percent of non-responders (14 donors) were not based at, nor followed up by Guy's Hospital; 2 of whom were also from overseas (The Gambia and Nigeria). 2 UK donors, who were both based at Guy's Hospital and also lived in London, did not attend their 12 month clinical appointment with the living donor co-ordinator and have since been lost to follow up.

One donor had declined to complete a questionnaire at 3 months due to his recipient (his wife) suffering 2 severe strokes shortly after transplantation. This donor declined the invitation to complete a 3 month questionnaire because he felt that he had too many other commitments with looking after his wife. He went on to complete a questionnaire at 12 months. This case was a tertiary referral to Guy's due to its complexity and the transplant being considered high risk.

Another donor’s recipient (his wife) died shortly after transplantation from sepsis and multi-organ failure. Despite telephone contact and an acknowledgement of having received the questionnaires, neither post-operative questionnaire was completed. This donor was the surviving parent to two young children and was again a tertiary referral to Guy's Hospital from a centre outside of London. Anecdotally, from conversations held with the living donor matron, this donor reported feeling extremely anxious at the thought of his donation and any potential return to Guy's Hospital, which may explain his reluctance to complete the questionnaires. Psychological support was offered to this donor, however due to him living a long way from London his follow up care was organised locally. It is not clear what psychosocial support he has been offered locally, nor whether he has decided to accept it.

The relationship between 2 donors and their recipients were known to have broken down within the first month after donation. One was a UK based donor who completed the 3 month questionnaire, however failed to complete the 12 month questionnaire. The second was from Nigeria and completed no post-operative questionnaires.

The UK based donor had donated to an ex-partner with whom he had remained good friends with after their relationship had broken down. This donor was seen in the follow up clinic 3 weeks after his donation, at which point he mentioned that he and his recipient were no longer on speaking terms. He said that his recipient had wanted to
resume a sexual relationship with him and after he had declined, she stated that she no longer wanted to be friends with him. This donor was offered psychological support but despite making an appointment to see one of the department psychologists, he failed to attend. This donor was not contactable by email, post or telephone at 12 months and failed to attend his 12 month follow up appointment in the living donor coordinator clinic.

The donor from Nigeria, who had donated to his cousin, returned home 3 months after donation. He contacted the living donor team and myself shortly after donation claiming that he was homeless following an argument with his recipient, who had changed the locks to his flat. An appointment was made for this donor to be seen at the hospital in order for both psychological and social support to be provided, however he failed to attend and chose to return to Nigeria. This donor has also not been contactable by email, post or telephone at 12 months. He also failed to attend his 12 month appointment, which he had originally intended to return to the UK for.

**Psychosocial measures**

Table 5.15 provides a summary of the 3 month and 12 month average scores for the psychosocial questionnaires, alongside the pre-operative scores. The differences between pre-operative and 3 month and pre-operative and 12 month questionnaire scores are also provided. A within-groups ANOVA was performed to compare differences over the three time points for those questionnaires with normally distributed data. The Friedman’s analysis of variance test was used for non-parametric data. As is evident from the Table 5.15, the differences between the questionnaire scores at the 3 different time points are very small. As a result, there was no statistically significant difference in scores for wellbeing, distress, mood, stress, life satisfaction, self-esteem, anxiety, optimism and social comparison. There was a statistically significant difference in the SF-12 (physical component) scores between the 3 time points: $\chi^2 = (2, 68) = 22.67, p<0.001$. Related-samples Wilcoxon signed ranked tests demonstrated a significant decrease in scores between pre-operative and 3 month scores ($p<0.001$) and between 3 month and 12 month scores ($p<0.001$) but no significant difference between pre-operative and 12 month scores ($p=0.134$).
Table 5.15: Summary of pre-operative, 3 month and 12 month scores for the psychosocial questionnaires

<table>
<thead>
<tr>
<th>Validated measures</th>
<th>Pre-operative averages</th>
<th>3 month averages</th>
<th>12 month averages</th>
<th>Difference Pre-op &amp; 3m</th>
<th>Difference Pre-op &amp; 12m</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>Score</td>
<td>SD / IQR</td>
<td>n</td>
<td>Score</td>
<td>SD / IQR</td>
</tr>
<tr>
<td>Wellbeing</td>
<td>100</td>
<td>29.51</td>
<td>5.693</td>
<td>80</td>
<td>29.46</td>
<td>5.512</td>
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<tr>
<td>Distress</td>
<td>94</td>
<td>10.22</td>
<td>4.532</td>
<td>77</td>
<td>9.35</td>
<td>4.866</td>
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<tr>
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<td>14.803</td>
</tr>
</tbody>
</table>

* p<0.05
† Non-parametric data: Medians, interquartile range and Mann-Whitney U test statistics presented
There was also a statistically significant difference in social support between the three time points: $\chi^2 (2, 70) = 10.29, p=0.006$. Related-samples Wilcoxon signed ranked tests demonstrated no significant difference between pre-operative and 3 month scores, or 3 month and 12 month scores however a significant difference (decrease) did exist between pre-operative and 12 month scores ($p=0.005$).

3 and 12 month psychosocial questionnaire responses vs. demographic data
Gender, age, religious beliefs and level of education were not associated with statistically significant differences for any of the psychosocial questionnaire responses at 3 or 12 months. Pre-operative differences in social comparison scores between white and non-white donors remained at 3 months, however they were no longer statistically significant by 12 months. This was due to a reduction in scores in the non-white group between 3 and 12 months ($t (8) = -1.255; p=0.245, 95\% \text{ CI } [-15.445, 4.556], d=-5.444$). Significant differences in distress scores between white and non-white donors which were seen pre-operatively were no longer present at 3 months ($t (75) = -1.060; p=0.292, 95\% \text{ CI } [-5.543, 1.692], d=-1.926$) or 12 months ($t (72) = -0.629; p=0.532, 95\% \text{ CI } [-4.466, 2.324], d=-1.071$).

3 and 12 month psychosocial questionnaire responses vs. medical, surgical and mental health history
Previous medical or surgical history was not associated with any statistically significant differences in the psychosocial questionnaire scores at 3 or 12 months. Pre-operative significant differences in self-esteem and social support in donors with a history of mental health illness were no longer statistically significant at 3 or 12 months.

3 and 12 month psychosocial questionnaire responses vs. transplant details
Differences in psychosocial questionnaire responses for parental and non-parental donors and primary and non-primary caregivers are discussed in detail in section 3 (sub-analysis).

Donation and transplant specific questions
Donors were asked a series of questions regarding their expectations of donation and their attitudes towards donation. Questions regarding expectations of donation were not answered by the unspecified donors as these questions referred to the recipient.
Expectations of Donation

Life after donation

The majority of donors agreed or strongly agreed that their recipient’s life was better having had a living donor kidney transplant (Figure 5.16). There was no statistically significant association between those disagreeing with the statement and recipient complications at either 3 months ($\chi^2 (5) = 9.591; p=0.088$) or 12 months ($\chi^2 (5) = 3.472; p=0.628$). Level of agreement with this question at both 3 and 12 months was not statistically significantly associated recipient dialysis status prior to transplantation.

![Figure 5.16: "My recipient's day-to-day life is much better now than before the transplant"](image)

Most donors neither agreed nor disagreed that their own lives had changed for the better after donation at both 3 and 12 month time points (Figure 5.17). Level of agreement with this question at both 3 and 12 months was not statistically significantly associated with any demographic factors, donor-recipient relationship nor primary caregiver status. There was also no statistically significant association with recipient dialysis status prior to transplantation. Most donors agreed or strongly agreed that the lives of others around them had changed for the better after donation at both 3 and 12 month time points, although there was slightly more agreement at 3 months (Figure 5.18). Level of agreement with this question at both 3 and 12 months was not statistically significantly associated with any demographic factors, recipient dialysis status, donor-recipient relationship nor primary caregiver status.
These results demonstrate that at both 3 and 12 months the majority of donors felt that their recipient and other people around them had benefited from receiving a living donor kidney transplant. The majority of donors felt that their own lives had not changed. These findings are in keeping with the expectations expressed in the pre-operative questionnaire.

Donor relationships (Specified Donors only)

At both 3 and 12 months, the majority of donors felt that the relationship between themselves and their recipient had either not changed or had improved since the transplant (Figure 5.19). The majority felt similarly towards their relationship with others in their social network (Figure 5.20). Five donors either disagreed or strongly
disagreed with the statement at 12 months. These donors included 1 who had separated from his wife, 1 whose recipient had suffered a debilitating stroke after transplantation and 1 who commented in the free-text space provided that her relationship with her adult son had deteriorated because he had become poorly motivated following the transplant and she had become frustrated that he was not moving on with his life. Another mentioned that her relationship with her recipient, who was her cousin, had improved in the lead up to donation but had subsequently deteriorated once the transplant had taken place. This donor had instigated the transplant by offering her kidney, which had led to an improvement in their relationship, however after the transplant the pair spoke to each other less often and saw each other less frequently, which made the donor feel "sad".

There were no apparent reasons for a decline in donor-recipient relationship for 2 of the donors. As documented in the above section "Non-responders", 2 donors who did not respond to either the 3 or 12 month questionnaires were known to have suffered a breakdown in their relationship with their recipient within the first 3 months after transplantation. One donor had donated to a distant family member and the other had donated to a friend. In total, 8% of donor-recipient relationships had either deteriorated (or were perceived to have deteriorated) within the first 12 months of transplantation.

Level of agreement with these questions at both 3 and 12 months was not statistically significantly associated with any demographic factors, donor-recipient relationship nor primary caregiver status.

![Bar chart](image)

*Figure 5.19: "On the whole, my relationship with my recipient is better now than before the transplant"*
Figure 5.20: “On the whole, my relationships with other people around me are better now than before the transplant”

Attitudes towards donation

By far the majority of donors felt that donating a kidney was one of the best things they had ever done (Figure 5.21). The majority of donors also felt good about being a living kidney donor (Figure 5.22). The answers given to either of these questions at both 3 and 12 months were not statistically significantly associated with any demographic factors, donor-recipient relationship nor primary caregiver status.

Figure 5.21: “Donating a kidney is one of the best things I have ever done”
In order to establish the level of post-operative regret, donors were asked whether or not, hypothetically, they would choose to be a living kidney donor again (Figure 5.23). By far the majority of donors disagreed or strongly disagreed with the statement "If I had my time again I would NOT choose to be a living kidney donor" both 3 months (N=73) and 12 months (N=65). This translates into a rate of regret of 6.8% at 3 months and 10.7% at 12 months. It was not possible to establish predictors of regret due to the small number of donors expressing evidence of regret. The majority of donors felt that they would continue to feel the same way about being a donor, regardless of what happened in the future (Figure 5.24).
Figure 5.24: "I will continue to feel the same way about being a Living Kidney Donor regardless of what happens in the future"

A large number of donors had been praised for being a living kidney donor (Figure 5.25), however only a small proportion felt that receiving praise for being a donor was important to them (3 months = 14.8%; 12 months = 22.7%) (Figure 5.26).

Figure 5.25: "I have been praised for being a Living Kidney Donor"
A large number of donors felt that their self-esteem had improved as a result of donating a kidney (Figure 5.27) and that donation had changed their outlook on life (Figure 5.28). A subjective feeling of improved self-esteem was not statistically significantly associated with any demographic factors, donor-recipient relationship, primary caregiver status or recipient outcomes. There was also no correlation between donors perceptions of self-esteem and answers given to the Rosenberg self-esteem questionnaire; that is, those stating that their self-esteem had increased after donation did not have an increase in their Rosenberg self-esteem questionnaire score. This is despite the 2 scores correlating significantly when assessed as part of the validation process ($r = 0.607; p = 0.003$). Donors who felt that living kidney donation had changed their outlook on life were correlated positively with 3 month wellbeing ($N=80, r=0.258, p=0.023$), self-esteem ($N=75, r=0.232, p=0.045$) and social comparison scores ($N=79, r=0.316, p=0.005$).
Summary of findings from Section 2

This section of data corresponds to the second hypothesis of the study: that on average there would be an improvement in wellbeing, life satisfaction, self-esteem and social comparison, distress, depression, stress and anxiety after donation and no change in physical health-related quality of life, social support and optimism scores after donation. As was demonstrated in Table 5.15, the differences in scores between the 3 different time points were very small and, for the majority of questionnaires, were neither clinically nor statistically significant.
Hypothesis 2.1 stated that wellbeing, life satisfaction, self-esteem and social comparison scores would increase after donation, whilst hypothesis 2.2 stated that distress, depression, stress and anxiety scores would decrease. These hypotheses were justified on the basis that the act of donation would result in a positive change in the donor's life, which would be reflected in an improvement in questionnaire scores. This would principally be as a result of the positive improvement in their recipient's health, quality of life and life prospects, and also from having done a good thing (i.e. helping someone or saving the life of someone you love). However, these results suggest that both in the short (3 months) and long-term (12 months) living donation makes neither a positive nor negative impact on the donors’ psychological state. These results have therefore failed to show either harm or benefit from living kidney donation and hypotheses 2.1 and 2.2 are therefore rejected.

Hypothesis 2.3 stated that social support and optimism scores would remain the same at 12 months. It also stated that physical health-related quality of life would decrease at 3 months before returning to baseline by 12 months. Optimism was unlikely to be affected by the process of donation as it relates more to a personality trait that may or may not have an impact on outcome, rather than being a trait that is changed by the process of donation. It was hypothesized that social support would remain the same because those supporting the donor at the time of donation were likely to still be providing the same supportive role at 12 months. Physical health-related quality of life was hypothesized to decrease at 3 months before returning to the pre-operative baseline, on the basis that the donor would still be recovering from surgery at 3 months but by 12 months they would have made a full recovery.

The results of the study only partially support hypothesis 2.3. Optimism scores were neither clinically nor statistically significantly different across the 3 time points. Social support scores decreased over time, with the most dramatic decrease occurring between 3 and 12 months. Social support was therefore found to be statistically significantly different over the 3 time points ($p=0.006$), however since the score only decreased by 4.5 points between the pre-operative and 12 month time points this may not translate into a clinically significant difference. As was hypothesized, physical health-related quality of life scores did decrease at 3 months (-2 points; $p<0.001$), however scores had not returned to the pre-operative baseline by 12 months. This resulted in there being a statistically significant difference in scores across the 3 time points ($p<0.001$). However, the very small difference in scores between the 3 time points was again unlikely to translate into a clinically significant difference.
Despite there being no objective evidence of benefit from the psychosocial questionnaire scores, some subjective benefit was seen in the answers given to the post-operative donation-specific questions. The majority of donors felt that their recipient’s day-to-day life had improved as a result of having received a living donor transplant. This was in keeping with the number of donors who had expected this outcome pre-operatively. A large number of donors also felt that donating a kidney was one of the best things they had ever done and they felt good about being a living donor. Donors had also been praised for donating a kidney and rates of regret and anticipated regret were also low. Donors subjectively felt that their self-esteem had improved, despite their being no corresponding increase in self-esteem as measured by the Rosenberg self-esteem questionnaire.

Other findings of interest included primary caregivers taking longer to return to normal than non-caregivers (9.1 weeks vs. 6.8 weeks) and the differences in 3 month psychological questionnaire scores between those who did and those who did not feel back to normal. Those who did not feel back to normal by 3 months were found to have lower wellbeing and higher distress, stress and anxiety than those who did feel back to normal. Despite extensive analysis of both pre-operative and 3 month data, it was not possible to predict or identify which factors were associated with not feeling back to normal by 3 months. Another interesting finding was the high proportion of donors whose relationship with their recipient had deteriorated within the first 12 months of donation (8%). Of these 7 donors, 3 had no contact with their recipient at all. In 2 of these cases, the donor-recipient pair had ceased contact less than 3 months after transplantation.

Section 3 – Sub-analysis of post-operative data

This section corresponds to Hypothesis 3; that the psychosocial wellbeing of a subset of donors will improve 12 months after donation (primary caregivers (Hypothesis 3.1.1) and parental donors (Hypothesis 3.1.2)) and a subset will decline 12 months after donation (donors who experienced post-operative complications (Hypothesis 3.2.1), donors whose recipients died or lost their graft within the study period (Hypothesis 3.2.2), donors whose recipients experienced post-operative complications (Hypothesis 3.2.3) and donors whose relationship with their recipient or others around them had deteriorated since the donation took place (Hypothesis 3.2.4)).
Primary caregivers (Hypothesis 3.1.1)

Table 5.16 provides pre-operative, 3 month and 12 month questionnaire scores for both primary and non-primary caregivers. Independent-samples t-tests and Mann-Whitney tests were performed to determine whether there was a statistically significant difference in each of the psychosocial questionnaire scores between primary caregivers and non-primary caregivers. A (3) x 2 mixed-ANOVA was performed for each psychosocial questionnaire, where possible, in order to determine whether primary caregivers and non-primary caregivers differed significantly in how their scores changed over the 3 time points. Friedman’s Two-Way Analysis of Variance by Ranks tests were performed for non-parametric data.

These data demonstrate that primary caregivers had significantly worse scores on a number of scales pre-operatively (wellbeing, distress, mood, stress, life satisfaction and anxiety) when compared to non-primary caregivers. By 3 months, these factors were no longer statistically significantly different between the 2 groups, primarily due to an improvement in scores in the primary caregiver group. The only psychosocial factor which was statistically significant between the 2 groups at 3 months was perceived social support, which was higher in the primary caregiver group (Median = 72 vs. 69; U=955.5; p=0.048). By 12 months the groups differed significantly on 7 out of the 11 psychosocial questionnaires. These included distress, mood, stress, life satisfaction and anxiety, which were all significantly different pre-operatively, and self-esteem and optimism, which were not significantly different pre-operatively. Wellbeing was the only psychosocial variable which did not return to being statistically different between the two groups at 12 months, having been statistically different pre-operatively.

Figures 29-39 appear to show that the psychosocial questionnaire scores follow different trajectories for both groups, with more variation in scores in the primary caregiver group. Mixed-ANOVAs were performed for wellbeing, distress, stress, self-esteem and optimism.
### Table 5.16: Pre-operative, 3 month and 12 month psychosocial questionnaire scores (Primary caregivers vs. Non-Primary caregivers)

<table>
<thead>
<tr>
<th></th>
<th>Pre-operative</th>
<th>3 months</th>
<th>12 months</th>
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<tbody>
<tr>
<td></td>
<td>Primary caregiver</td>
<td>Non-primary caregiver</td>
<td>Primary caregiver</td>
</tr>
<tr>
<td></td>
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<td>Score</td>
<td>SD / IQR</td>
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<td>3</td>
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<td>Life Satisfaction†</td>
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<td>11</td>
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<td>Optimism</td>
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<td>Social Comparison</td>
<td>41</td>
<td>69.17</td>
<td>15.965</td>
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* p<0.05
† Non-parametric data: Medians, interquartile range and Mann-Whitney U test statistics presented

HRQoL: Health-Related Quality of Life (SF12 physical components only)
The only mixed-ANOVA which demonstrated a statistically significant interaction between caregiver status and questionnaire time point was for self-esteem \((F(2,130) = 3.410, p =0.036, \text{ partial } \eta^2 = 0.050)\) (Figure 5.29). Pre-operatively and at 3 months the 2 groups were not statistically significantly different. Self-esteem scores in the non-primary caregiver group increased at 12 months, whereas scores in the primary caregiver group decreased. As a result, self-esteem scores at 12 months were statistically significantly different \((t (74) = 2.311; p=0.024, 95\% \text{ CI } [0.345, 4.655], d=2.50)\).

![Mixed ANOVA: \(F(2,130) = 3.410, p =0.036, \text{ partial } \eta^2 = 0.050\)
Tests of between-subjects effects:
\(F (2, 1) = 5.341, p = 0.024, \text{ partial } \eta^2 = 0.067\)](image)

**Figure 5.29: Self-esteem (Primary caregivers vs. Non-primary caregivers)**

The mixed ANOVA for wellbeing scores did not demonstrate a statistically significant interaction between primary caregiver and non-primary caregivers. Despite this, wellbeing was only psychosocial variable which was no longer statistically significantly different between the 2 groups at 3 and 12 months.

![Mixed ANOVA: \(F (2, 138) = 2.70; p=0.071, \text{ partial } \eta^2=0.038.\)
Tests of between-subjects effects:
\(F (1, 69) = 7.867, p=0.007, \text{ partial } \eta^2 = 0.102\)](image)

**Figure 5.30: Wellbeing (Primary caregivers vs. Non-primary caregivers)**
Distress and stress scores were both statistically significant between the 2 groups pre-operatively (Table 5.16). Despite a transient improvement in scores in the caregiver group at 3 months, by 12 months the 2 groups were statistically significantly different once again due to a subsequent decline in the primary caregiver group. Distress scores returned to their pre-operative baseline (Figure 5.31) and stress scores exceeded the pre-operative baseline (Figure 5.32).

**Figure 5.31: Distress (Primary caregivers vs. Non-primary caregivers)**

![Distress Scores Graph](Image)

**Mixed ANOVA: F (2, 124) = 0.762; p=0.469, partial η²=0.012**

**Tests of between-subjects effects:**

$F (1, 62) = 10.101, p=0.002, \text{ partial } \eta^2 = 0.140$

**Figure 5.32: Stress (Primary caregivers vs. Non-primary caregivers)**

![Stress Scores Graph](Image)

**Mixed ANOVA: F (2, 140) = 1.675; p=0.191, partial η²=0.023**

**Tests of between-subjects effects:**

$F (1, 70) = 9.830, p=0.003, \text{ partial } \eta^2 = 0.123$

Optimism scores were not statistically significantly different between the 2 groups pre-operatively or at 3 months. However optimism decreased in the primary caregiver group and increased in the non-primary caregiver group; therefore scores were statistically significantly different between the 2 groups at 12 months.
Related-samples Friedman's Two-Way Analysis of Variance by Ranks tests were performed for the mood, health-related quality of life, life satisfaction, anxiety, social support and social comparison questionnaires. The Friedman's test demonstrated that there was no statistically significant change in scores over the 3 time points for mood (Primary Caregiver: $\chi^2(2) = 3.805; p=0.149$; Non- primary Caregiver: $\chi^2(2) = 1.348, p=0.510$), life satisfaction (Primary Caregiver: $\chi^2(2) = 0.311; p=0.856$; Non- primary Caregiver: $\chi^2(2) = 0.331; p=0.848$) and social comparison (Primary Caregiver: $\chi^2(2) = 2.333; p=0.331$; Non- primary Caregiver: $\chi^2(2) = 0.628; p=0.731$) for either the primary caregiver or the non-primary caregiver group.

Physical health-related quality of life scores (Figure 5.34) in the non-primary caregiver group decreased from 29.0 pre-operatively to 27.0 at 3 months before increasing above baseline to 29.5 at 12 months. There was no statistically significant difference between the 3 time points for the non-primary caregiver group and therefore the Friedman's test was not statistically significant. In the primary caregiver group, median SF-12 scores also dropped from 29.0 pre-operatively to 27.0 at 3 months ($z = -4.076; p<0.001$). At 12 months the score had increased to 28.0 (1.5 points below that in the non-primary caregiver group), which therefore resulted in the Friedman test being statistically significant.
There was no statistically significant change in anxiety scores over the 3 time points for the non-primary caregiver group (Figure 5.35). In the primary caregiver group, there was a statistically significant change in scores over the 3 time points, resulting in a statistically significant Friedman's test. Pairwise comparisons were performed with a Bonferroni correction for multiple comparisons and demonstrated that anxiety scores were significantly different between the pre-operative and 3 month time points \( (p=0.006) \). Primary caregivers were significantly more anxious pre-operatively than the non-carers \( (Mdn = 12 \text{ vs. } 9) \). At 3 months there was no longer a statistically significant difference between the 2 groups due to an improvement in the primary caregiver group \( (U = 849.5; \ p=0.367) \). By 12 months, anxiety scores had increased towards pre-operative baseline in both groups, which therefore meant they were again statistically significantly different.
There was no statistically significant change in social support scores over the 3 time points for the primary caregiver group (Figure 5.36). There was a statistically significant change in scores over the 3 time points for the non-primary caregiver group. Pairwise comparisons were performed with a Bonferroni correction for multiple comparisons and showed that social support scores for the non-primary carer group were significantly different between the pre-operative and 3 month time points ($p=0.017$).

Social support scores were not statistically significantly different between the 2 groups pre-operatively ($Mdn = 72$ for both groups; $U = 1219.5$; $p=0.754$). At 3 months, scores remained stable in the primary caregiver group, however significantly decreased in the non-primary caregiver group. The 2 groups were therefore statistically significantly different. At 12 months there was no longer a statistically significant difference between the 2 groups ($U = 751.0$; $p=0.919$) due to the same reduction in scores in the primary caregiver group.

![Figure 5.36: Social Support (Primary caregivers vs. Non-primary caregivers)](image)

Friedman’s Test:
- Primary Caregiver: $\chi^2 (2) = 3.873$; $p=0.144$
- Non-primary Caregiver: $\chi^2 (2) = 9.669$; $p=0.008$
Table 5.17 provides pre-operative, 3 month and 12 month questionnaire scores for both parental and non-parental donors. This data is displayed graphically in figures 37 and 38. Independent-samples t-tests and Mann-Whitney tests were performed to determine whether there was a statistically significant difference in each of the psychosocial questionnaire scores between parental and non-parental donors. A (3) x 2 mixed-ANOVA was performed for each psychosocial questionnaire, where possible, in order to determine whether parental and non-parental donors significantly differed in how their scores changed over the 3 time points. In the event of non-parametric data or heterogeneity a Friedman's Two-Way Analysis of Variance by Ranks test was performed.

These data demonstrate that parental donors had significantly worse pre-operative scores for wellbeing, distress, stress and life satisfaction when compared to non-parental donors. By 3 months, distress and life satisfaction scores had improved, such that the 2 groups were no longer statistically significantly different and this remained the case at 12 months. Wellbeing scores remained statistically significantly different between the 2 groups at 3 months, however were no longer so at 12 months due to an improvement in the parental donor group.

At 12 months, stress and physical health-related quality of life scores were the only 2 questionnaire scores that were statistically significantly different between the 2 groups. Stress scores remained significantly different between the 2 groups at all 3 time points. Physical health-related quality of life was not statistically significantly different between the 2 groups pre-operatively. Scores in both groups decreased at 3 months, however whilst scores in the non-parental group had increased above baseline by 12 months, they remained low in the parental donor group.

Mixed-ANOVA were performed for wellbeing, distress, stress and self-esteem, none of which demonstrated a statistically significant interaction between parental donor status and questionnaire time point (Wellbeing: $F (2, 138) = 0.915; p=0.403$, partial $\eta^2=0.013$; Distress: $F(2, 124) = 1.209; p=0.302$, partial $\eta^2 = 0.019$; Stress: $F (2, 140) = 1.219; p=0.299$, partial $\eta^2=0.017$; Self-esteem $F (2, 130) = 0.038; p=0.962$, partial $\eta^2=0.001$).
## Table 5.17: Pre-operative, 3 month and 12 month psychosocial questionnaire scores (Parental vs. Non-Parental Donors)

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<tr>
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<td>Social Comparison</td>
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<td>68.59</td>
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* p<0.05  
† Non-parametric data: Medians, interquartile range and Mann-Whitney U test statistics presented

HRQoL: Health-Related Quality of Life (SF12 physical components only)
For each of these measures, scores in the parental donor group remained worse than the non-parental group at all 3 questionnaire time points. Tests of between-subjects effects demonstrated a statistically significant difference between the 2 groups for wellbeing ($F(1, 69) = 5.094, p=0.027$, partial $\eta^2 = 0.069$), distress ($F(1, 62) = 10.156$, $p=0.002$, partial $\eta^2 = 0.141$) and stress ($F(1, 70) = 11.720$, $p=0.001$, partial $\eta^2 = 0.143$) but not for self-esteem ($F(1, 65) = 2.307$, $p=0.134$, partial $\eta^2 = 0.034$).

Friedman's Two-Way Analysis of Variance by Ranks tests were conducted for mood, physical health-related quality of life, life satisfaction, anxiety, social support, optimism and social comparison scores. There was no statistically significant change in scores over the 3 time points for mood (Parental donor: $\chi^2 (2) = 1.219; p=0.544$; Non-parental donor: $\chi^2 (2) = 4.156; p=0.125$), life satisfaction (Parental donor: $\chi^2 (2) = 0.845; p=0.655$; Non-parental donor: $\chi^2 (2) = 0.671; p=0.715$), anxiety (Parental donor: $\chi^2 (2) = 2.467; p=0.291$; Non-parental donor: $\chi^2 (2) = 1.178; p=0.555$), optimism (Parental donor: $\chi^2 (2) = 1.918; p=0.383$; Non-parental donor: $\chi^2 (2) = 0.180; p=0.914$) or social comparison (Parental donor: $\chi^2 (2) = 4.4598; p=0.108$; Non-parental donor: $\chi^2 (2) = 1.455; p=0.483$) for either group. Life satisfaction was the only measure to be statistically significantly different between the 2 groups pre-operatively. There were no statistically significant differences between the 2 groups for any of the measures at 3 and 12 months.

For physical health-related quality of life, Friedman's Two-Way Analysis of Variance by Ranks tests was statistically significantly different for both parental and non-parental donors (Figure 5.37). Pairwise comparisons were performed with a Bonferroni correction for multiple comparisons for both groups. In the parental donor group scores were found to be statistically significantly different between 3 month and 12 month time points ($p=0.019$). In the non-parental donor group scores were statistically significantly different between both the pre-operative and 3 month time points ($p=0.016$) and 3 month and 12 month time points ($p=0.001$).
For social support, Friedman's Two-Way Analysis of Variance by Ranks tests was not statistically significant for the parental donor group. It was statistically significant in the non-parental donor group (Figure 5.38) and pairwise comparisons with a Bonferroni correction for multiple comparisons demonstrated that scores were statistically significantly different between the 3 and 12 month time points ($p=0.045$).
Psychosocial questionnaire responses vs. donor recovery (Hypothesis 3.2.1)
Having a complication, readmission to hospital and the need for surgery for complications were not associated with statistically significant differences in any of the psychosocial questionnaires pre-operatively, or at 3 or 12 months. Of note, 1 donor who had experienced post-operative complications had PHQ-2 mood score indicative of low mood (≥3) at 12 months.

Psychosocial questionnaire responses vs. recipient complications, transplant failure, recipient death (Hypotheses 3.2.2 and 3.2.3)
This study had insufficient numbers to detect differences related to transplant failure and recipient death. 2 donors who completed the 12 month questionnaire noted that their recipient had lost their kidney. Both of these donors had a PHQ-2 mood score indicative of low mood (≥3) at 12 months. Only 1 recipient is known to have died and the corresponding donor did not complete questionnaires at either 3 or 12 months. Transplant failure has therefore been grouped with recipient complications and analysed accordingly.

At 3 months, 23 donors (26.1%) stated that their recipient had suffered a complication during the first 3 months after transplantation. There was no statistically significant difference in any of the 3 month psychosocial questionnaire scores between those whose recipients had and had not suffered a complication. At 12 months, a further 15 donors (17.0%) stated that their recipient had suffered a complication during the first year after transplantation. Those donors whose recipients had suffered a complication were found to be lower in mood (Mdn = 1.0) than those whose recipients had not suffered a complication (Mdn=0); U=722.5; p=0.031; however this 1-point difference is unlikely to represent a clinically significant difference between the 2 groups.

Donor relationships at 12 months (Hypothesis 3.2.4)
There was no statistically significant difference in 12 month psychosocial questionnaire scores between those whose relationship with their recipient had stayed the same or improved after donation when compared to those whose relationship with their recipient had declined. Two donors who reported a deterioration of their relationship with their recipient had a PHQ-2 mood score indicative of low mood (≥3) at 12 months. There was also no statistically significant difference in 12 month psychosocial questionnaire scores between those whose relationship with others
around them had stayed the same or improved after donation when compared to those whose relationship with others around them had declined.

**Summary of findings from Section 3**
The results presented in section 3 demonstrate that for some psychosocial factors, primary caregivers and parental donors follow a statistically significant different trajectory over the 3 time points when compared to their non-primary caregiver and non-parental donor counterparts.

Hypothesis 3.1.1 stated that primary caregivers would demonstrate an improvement in questionnaire scores 12 months after donation. The only psychological measure which demonstrated a sustained improvement at 12 months was wellbeing, however the change in wellbeing score before surgery and at 12 months was not statistically significantly different ($t (36) = 1.443; p=0.158, 95\% CI [-0.624, 3.705]$). The 3 month improvements in scores for distress, stress, life satisfaction and anxiety were only transient and had almost returned to baseline by 12 months. A statistically significantly difference between the 2 groups had therefore re-emerged by 12 months, with the primary caregiver group scoring worse than the non-primary caregiver group across each of these measures. Mood, physical health-related quality of life, self-esteem, social support, optimism and social comparison scores were all worse at 12 months than pre-operatively, however the change in scores was only statistically significant for physical health-related quality of life ($z = 88.5; p=0.015$). Hypothesis 3.1.1 was therefore rejected.

Hypothesis 3.1.2 stated that parental donors would demonstrate an improvement in questionnaire scores 12 months after donation. The only psychological measure which demonstrated a sustained improvement at 12 months was wellbeing, however there was no statistically significant difference between pre-operative and 12 month wellbeing scores ($t (31) = 0.265; p=0.793, 95\% CI -1.677, 2.177$). Three month improvements in scores for distress, life satisfaction, anxiety and social support were only transient and had almost returned to baseline by 12 months. Stress, physical health-related quality of life, self-esteem, optimism and social comparison scores were all worse at 12 months than pre-operatively, however none of these changes in scores were found to be statistically significant. Hypothesis 3.1.2 was therefore rejected.
Hypothesis 3.2.1 stated that donors who experienced post-operative complications would demonstrate a decline in scores at 12 months. The hypothesis was rejected on the basis that there were no significant differences in any of the psychosocial questionnaires at 12 months between those who had and those who had not experienced a post-operative complication.

Hypothesis 3.2.2 stated that donors whose recipients had died or lost their kidney within the study period would demonstrate a decline in scores at 12 months. It was not possible to accept or reject this hypothesis due to an insufficient sample size. Recipient deaths and graft loss were therefore grouped with recipient post-operative complications (hypothesis 3.2.3). At 12 months, donors whose recipients had suffered a complication were found to be lower in mood than those donors whose recipients had not suffered a complication, however the difference in scores was so small (1 point) that this was is unlikely to translate into a clinically significant difference. Hypothesis 3.2.3 was therefore rejected.

Hypothesis 3.2.4 stated that donors whose relationships with their recipient or others around them had deteriorated since the donation took place would demonstrate a decline in scores at 12 months. This hypothesis was rejected on the basis of no statistically significant differences for any of the psychosocial questionnaires.

Discussion
This study is one of very few prospective, longitudinal, quantitative studies that has attempted to make a comprehensive assessment of psychosocial outcomes following living kidney donation. It is the first study to use such a broad range of validated psychosocial measures alongside purposely written and piloted questions specific to donation. This study has addressed a number of the criticisms highlighted by the systematic review conducted by Clemens and colleagues (Clemens et al., 2006). As well as being prospective, longitudinal and comprehensive this study has reported extensive demographic data and has included an even gender split, a broad range of ages and donors from different parts of the UK, all of whom donated at one transplant centre. All the donors in this study also self-completed questionnaires at set time points and 2 post-operative questionnaires were completed 9 months apart in order to capture data across both short and medium-long term recovery periods. Information on mental health rates and non-responders was also presented, and an attempt was made to identify why certain individuals had failed to complete the post-operative
questionnaires. The purposely designed questions had undergone pilot testing and had demonstrated reasonable reliability and validity. There are a number of key findings from this study which are discussed in detail below.

Section 1
Section 1 corresponded to the first hypothesis of the study; that there would be a number of donor and transplant-related factors that would be associated with poorer than average psychosocial questionnaire scores pre-operatively. These included being a parent to the recipient, being a primary caregiver to the recipient, donating to a recipient who was on dialysis, being asked to donate and being the only potential living donor.

Hypotheses 1.1 and 1.2 (Parental donors and primary caregivers)
The first key finding corresponding to hypothesis 1 was that parental donors and primary caregivers had a significantly higher pre-operative stress and distress and lower wellbeing and life-satisfaction. Additionally, primary caregiver donors also demonstrated significantly higher anxiety and lower mood than non-primary caregivers. There are a number of similarities between parental and primary caregiver donors that may explain why both groups scored worse across a range of psychological questionnaires prior to donation. Whilst many parental donors were also primary caregivers to their recipient, one must also consider what it means to be either a parent or primary caregiver. Both roles reflect a certain degree of emotional closeness between the donor and the recipient, which is not always present in every living donor-recipient pair. As demonstrated in the qualitative study outlined in chapter 3, a closer relationship between donor and recipient means that the recipient's health has more of an emotional or psychological impact on the donor, as well as affecting other physical and social aspects of life.

There are no currently published studies that consider the impact of caregiver status on living kidney donors, although the issue of multiplicity of roles within the recovery period has been documented as making recovery from living donor surgery more difficult (Tong et al., 2012a). Studies into parental donation have reported emotional strain and psychiatric symptoms within parental donors both before and after donation (Gold et al., 1986, Karrfelt et al., 1998). As described in chapter 3, parents are likely to have endured a period of uncertainty prior to their child's diagnosis being made, after which they must then adapt to life with a chronically sick child. This in
itself is extremely distressing and stressful and is associated with feelings of guilt. In addition, depending on the age of the child at diagnosis, many parents also take on the responsibility for managing their child’s healthcare, on top of all the other important aspects of childcare. This includes dialysis, regardless of whether the child dialyses at home or in the hospital, and the crucially important supportive care, which includes administering multiple different drugs at different times of the day, plus strict adherence to fluid and dietary intake. This latter point regarding responsibility for managing healthcare is also applicable to the primary caregiver group and is discussed in more detail below.

In addition, the diagnosis of renal failure is also one that carries with it the possibility of fatality. As was noted in the qualitative study, parents of young children frequently endured an acute episode, either before or after the diagnosis of renal failure was made, where their child’s health deteriorated rapidly and where there was a very real possibility that they may die. The vivid memories of episodes such as these, and the feelings of desperation associated with willing their child to live, provide the most likely explanations for why such a high proportion of parents (97.4%) stated that they made their decision to donate instantly. Parents are likely to remember how they felt at the time when their child was critically ill and it follows that living donation provided a way to save their child’s life. Their decision to donate therefore remained a life-saving decision, even though the donation may have actually taken place once the child had stabilised and there was no longer an immediate threat to life.

The age of the recipient from parental donors was not found to be associated with any differences in the pre-operative psychosocial questionnaire scores. Anecdotally, donations to very young recipients are usually seen as being more stressful, simply due to the fragility of the child. This study has demonstrated that age is insignificant within the context of parental living kidney donation; that is, the psychosocial impact on a parental donor is the same however young or old their child may be. It is therefore no surprise that parental donors demonstrated higher stress and distress, and lower wellbeing and life satisfaction before donation.

The differences demonstrated between primary caregiver and non-primary caregiver donors can be explained for similar reasons as noted above. Primary caregivers, regardless of what biological relationship they may have with their recipient, are likely to have undergone a similar period of adjustment following a diagnosis of renal failure
due to their close emotional relationship with their recipient. As was discovered in the qualitative study, primary caregivers felt restricted not only by their caregiver duties but additionally by the impact of renal disease on their recipient. This was a particular issue for spousal donors whose lives with their recipient had changed dramatically following their diagnosis of renal failure.

Caregiver burden is a well-established concept within health psychology, however has not previously been considered within the living kidney donor population. It is often something that is overlooked by clinicians (Adelman et al., 2014) and has been defined as “the extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical, and spiritual functioning” (Zarit et al., 1986). Caregiving may include a range of activities, such as assistance with basic activities of daily living, medication management, scheduling and accompanying individuals to hospital appointments, and more technically skilful tasks such as home-based dialysis. A number of risk factors have been identified for developing caregiver burden and many of these are easily identifiable within the living donor population.

Parental and spousal donors made up the majority of the caregiver sample in this study. Both of these groups of donors are at high risk of experiencing caregiver burden as they are likely to reside with the care recipient, experience social isolation and financial stresses, provide care for a large number of hours and have a lack of choice in being a caregiver (Adelman et al., 2014). The factors listed above correspond perfectly with the negative impact of primary caregiver status described in the qualitative study. Given the multidimensional nature of caring for an individual with renal failure (that is, the sheer number of different tasks that are required to help manage the condition) it is again unsurprising that primary caregiver donors were found to have higher stress and distress, and lower wellbeing and life satisfaction before donation.

Decreased mood and increased anxiety appear to be unique to the primary caregiver group as these were not found to be statistically significant between parental and non-parental donors. The differences in both pre-operative mood and anxiety may be explained by caregiver burden, but one must also remember that these individuals are also about to undergo major surgery themselves. Not only must they make their own preparations for surgery, a stay in hospital and a period of convalescence but, due to the very nature of their primary caregiver role, they must also prepare their recipient for the same events. In addition, the same individuals are also very likely to resume
their caregiver role as soon as their recipient returns home from hospital. Instead of managing dialysis and medication to treat the symptoms of renal failure, primary caregiver donors must adapt to managing the particular needs of a person with a new transplant, such as thrice weekly clinic visits, administering complex regimes of anti-rejection medications and close monitoring of the recipient for signs of infection and complications. It is likely that a combination of impending surgery, the associated risks for themselves and their recipient, plus these new impending responsibilities may account for the decreased mood and increased anxiety in the pre-operative period. Additionally, primary caregivers may also be anxious about who takes on their role as primary caregiver whilst they are recovering from surgery, and also who would take on their role in the medium or long term should they suffer a complication during or after donor surgery.

**Hypothesis 1.3-1.5 (Recipient dialysis status, being asked to donate and availability of other donors)**

Hypotheses 1.3 stated that those donors whose recipients were on dialysis would be more distressed pre-operatively. This was because the qualitative study suggested that these donors found it distressing to see their recipient experiencing the negative sequelae of dialysis. The lack of distress in donors with recipients on dialysis may be related to the proximity of the transplant in relation to when the questionnaire was completed. Each donor completing the questionnaire was only weeks away from donation, which in turn meant that there was “light at the end of the tunnel” and their recipient’s need for dialysis was coming to an end. It may well be that had distress been measured earlier in the workup process that there would have been a significant difference between the 2 groups.

Another potential explanation is that both groups were equally distressed, but for different reasons. Although the process of dialysis is distressing for both the recipient and the donor for a number of reasons, the lives of pre-emptive patients are often similarly restricted because of their symptomology, which may also have a distressing impact on the donor. It is commonly the case that renal failure patients who are awaiting a living donor transplant try and hold off starting dialysis if at all possible. By doing so, they do not receive the physiological benefits of dialysis and the ongoing accumulation of toxins within the body means that they often feel more unwell than someone on dialysis. This therefore means that both donors with and without
recipients on dialysis may be equally distressed; one group due to the negative aspects of dialysis and the group due to the negative aspects of not being on dialysis.

Hypotheses 1.4 stated that increased pre-operative stress, anxiety and distress would be demonstrated in those who were asked to donate. This hypothesis was rejected, however very small numbers of donors were asked to donate (6 donors) so it is likely that this study was underpowered to answer this particular question. Hypothesis 1.5 stated that increased pre-operative stress, anxiety and distress would be demonstrated in those who were the only available donor. This was not found to be the case and therefore this hypothesis was also rejected. This may represent a true lack of difference between the 2 groups, or may reflect a period of adjustment between the moment the donor was told that they were the only suitable candidate and the donation. Given that the majority of donors took more than 6 months to donate, this latter explanation would have to be excluded prior to definitively rejecting this hypothesis. One way of doing this would be to capture additional data at more than 1 pre-operative time point; ideally on the very first occasion that the potential donor attends the transplant centre.

**Section 1 - Other**

A number of additional interesting findings unrelated to the primary hypotheses were identified in section 1. The sample included 27 donors who had a history of past or current mental health illness. This is in keeping with figures published by the Office for National Statistics in 2009 which reported that nearly one person in four in England has experienced at least one psychiatric disorder, with 7.2% experiencing 2 or more psychiatric disorders (Office of National Statistics, 2009). Given that the psychological impact of having a relative of friend with renal failure can be quite significant, it would not have been surprising if this rate been higher. Reassuringly, all of the donors with a history of mental health illness had sought help; however 7 donors (25.9% of those with a history of mental illness) had not been referred for a mental health assessment as part of their donor workup. In 6 of these cases, there was no documented history of a mental health illness in the donor’s hospital notes.

For an additional 60 donors (who all denied mental health issues when questioned by the researcher) there was no documentation of any member of the transplant team having enquired about their mental health history. As there was no documentation, it is not possible to ascertain whether donors were ever asked about their mental health,
or whether they were asked but denied any issues (and therefore this was subsequently not documented). It is possible that donors may have felt that their mental health history was not relevant and therefore did not volunteer this information to the transplant team, or possibly that they deliberately chose not to conceal their mental health history in fear of being turned down as a donor.

Another interesting finding was the number of living donors who were registered on the NHS organ donor register (49%). Whilst this is higher than the average for the UK population (31%) (NHS Blood and Transplant, 2013), one may have expected this to be even higher given that living donors have a first-hand experience of a loved one in need of a transplant. The statistically significantly higher rate in organ donor register registrations in unspecified donors is in keeping with findings from other studies (Maple et al., 2014), as is the statistically significantly lower rate of organ donor register registrations found in non-white donors (Deedat et al., 2013).

The demographic and donation-specific questions provided evidence in support of other published studies, as well as new data related to topics that have not been addressed previously. This study found that the majority of donors offered to donate and made their decision instantly, and this finding is in keeping with a number of other studies (Eggeling, 2000, Andersen et al., 2005, Brown et al., 2008, Gill and Lowes, 2008, Smith et al., 2011, McGrath et al., 2012).

New findings include the increase in pre-operative distress and anxiety demonstrated in incompatible living kidney donors. This can be explained by the additional risks associated with incompatible transplantation, such as rejection, graft loss and recipient death, which are discussed at length and on numerous occasions throughout the living donor workup process. This study is also the first to ask detailed questions regarding the issues that may be concerning living donors in the weeks leading up to their transplant. This study has demonstrated that significant proportions of donors think about an aspect of their donation once a day or more. These include the decision to become a donor, the process of donation and the social consequences of their donation. Worrying about the recipient is also common; 35% worry about their recipient or something going wrong with the transplant at least once a day.
Section 2

Section 2 corresponded to the second hypothesis of the study; that on average, scores across a number of measures would show an improvement after donation. Hypotheses 2.1 and 2.2 respectively stated that wellbeing, life satisfaction, self-esteem and social comparison would improve after donation, and that distress, depression, stress and anxiety would decrease after donation. Hypothesis 2.3 stated that at 12 months physical health-related quality of life, social support and optimism would remain the same as the pre-operative scores.

This study failed to demonstrate a statistically significant improvement in wellbeing, life satisfaction, self-esteem, social comparison, distress, depression, stress and anxiety after donation. As is shown in Table 5.15, the differences in scores between the 3 different time points were very small and, for the majority of questionnaires, was neither clinically nor statistically significant. An unexpected finding was the steady decrease in social support scores after donation and the failure of health-related quality of life scores to return to baseline by 12 months. The differences in social support and health-related quality of life were again very small and although they were statistically significant, they are unlikely to translate into a clinically significant difference. This study is therefore unable to demonstrate any objective psychosocial benefits from donating a kidney. As discussed in detail in chapter 1, this has enormous significance for the practice of living kidney donation because it means that the transplant community are actively encouraging a practice which goes against the very basic principles of medical ethics. One is therefore prompted to consider whether the practice of living donation should be allowed to continue.

The reasons for these results are unclear but may possibly be due to the relatively short time period over which the study was conducted. It may be that the benefits of living kidney donation become more significant after the first year of transplantation. This may be because the 1 year anniversary of the transplant may be an unofficial or undisclosed target date that donors wish to reach before deeming the transplant a success. Additionally, the positive impact on some donors may be counteracted by the negative impact on others, which results in no net significant difference across the 3 time points.

Another consideration is that the pre-operative questionnaire was completed just 2-4 weeks prior to donation taking place. Given that the donation process would have
taken a significant amount of time, it is possible that the answers given at this stage in
the donation process are not the donors’ true baseline. The reason for this is that in the
earlier stages the donor is not certain that the transplant will go ahead and this,
coupled with the worries related to having a loved one with renal failure, may be
associated with lower levels of wellbeing and life-satisfaction, and higher amounts of
stress, distress, depression and anxiety. In the weeks leading up to donation, the donor
can be more confident that their donation will go ahead and this may ease some of the
psychosocial issues that they may have been experiencing over the preceding months
or years.

When reviewing the existing literature, a number of the psychosocial factors measured
in this study have previously been measured in the living kidney donor population and
reported in the literature. These include psychological wellbeing, depression, anxiety,
stress, health-related quality of life and social factors. Regret and donor benefit have
also been discussed within a small number of studies.

**Wellbeing**

This is the first study to identify lower wellbeing in particular groups of donors;
including parental donors and primary caregivers. This study failed to demonstrate
the improvement in happiness and wellbeing that has been demonstrated in other
studies (Duque et al., 1999, Corley et al., 2000, Fisher et al., 2005, Jackobs et al., 2005).
In these studies large proportions of donors felt happy (Corley et al., 2000) or happier
since their donation took place (Duque et al., 1999, Fisher et al., 2005, Jackobs et al.,
2005). However, given that all of these studies were retrospective it is difficult to
exclude the influence of recall bias, especially when some donors were completing
questionnaires over 20 years after donation (Corley et al., 2000).

Whilst this study failed to demonstrate an improvement in happiness and wellbeing, it
also failed to demonstrate a significant decline. Some less positive outcomes were
experienced in this sample that have also been reported elsewhere. These included
feelings of abandonment and reduced social support (Smith et al., 1986),
disappointment, sadness and loss (Fisher et al., 2005, Dahm et al., 2006) and feelings of
guilt in the event of adverse recipient outcomes (graft loss or death) (Brown and
Sussman, 1982, Schover et al., 1997).
**Depression**

There are only 4 reported studies that have prospectively assessed depression in living kidney donors using a validated measure. This study demonstrated no difference in pre- and post-operative depression scores, which is in keeping with the results presented by Virzi et al (2007) and Kroencke et al (2012). Kroencke and colleagues sampled 79 donors at the same time points as this study, whereas Virzi and colleagues sampled 48 donors before donation and 4 months after donation.

A significant worsening of mood was demonstrated in 2 studies, both of which were of similar size to those that reported no significant difference (75 donors in Minz et al (2005); 45 donors in Lopes et al (2011)). Despite a reasonable sample size both studies attributed their negative findings to only a small number of donors. For example, Minz and colleagues (2005), who used the Beck's Depression Inventory (BDI), concluded that depression scores were significantly worse 3 months after donation, despite only 4 donors demonstrating evidence of mild depression. It is unclear from the results and analysis presented in the paper where these conclusions have been drawn from and therefore the results must be interpreted with caution. Previously reported factors associated with increased rates of depression included negative recipient outcomes (Kroencke et al., 2012) and being single (Wiedebusch et al., 2009), however these were not replicated in this study.

**Anxiety**

Only 7 studies have prospectively measured anxiety. This study demonstrated no change in anxiety following donation and this is again in keeping with the study by Virzi and colleagues (2007). On previous occasions where donor anxiety has been measured prospectively, the results have been contradictory with some demonstrating an improvement, some demonstrating a decline and others demonstrating no change. No factors had previously been identified as predictors of increased anxiety within living donors. Whilst this study has not been able to identify any predictors of anxiety, it has demonstrated that donating to an incompatible recipient correlates with both higher distress and anxiety. The reasons for this are discussed above.

This study has also identified that increased pre-operative anxiety correlates significantly with the amount of time spent thinking about different aspects of the donation process. These include the decision to become a living donor, the process of donation, their social circumstances and the recipient. Whilst one cannot be certain
that correlation implies causality, it would be perfectly reasonable to infer that the increase in pre-operative anxiety is closely related to the impending surgery. In addition to pre-operative anxiety being higher in parental donors and primary caregivers, post-operative anxiety is also higher. The reasons for this are discussed below.

**Stress**
Stress within the living kidney donor population was commonly referred to within the living donor literature, however this was primarily within the context of identifying possible causes of stress in the living donor population. This study is the first to measure stress prospectively using a validated measure and has demonstrated no change over time. This is the first study to demonstrate an increase in stress in parental donors and in donors who are primary caregivers.

**Health-related Quality of Life (HRQoL)**
The assessment of HRQoL in this study was limited to the physical components of the SF-12. This study has shown that physical HRQoL scores decreased by 2 points at 3 months and remained 1 point below the pre-operative score at 12 months. This resulted in there being a statistically significant difference in scores across the 3 time points; however this very small difference is unlikely to translate into a clinically significant difference.

These findings are partially in keeping with other prospective studies that have used the short-form measures; the majority of which have also demonstrated a drop in total score, the physical component score and the mental component score after donation (Shrestha et al., 2008, Virzi et al., 2007, Chien et al., 2010, Kroencke et al., 2012, Bahler and Sundaram, 2013, Smith et al., 2004, Bergman et al., 2005, Lumsdaine et al., 2005). This study has failed to demonstrate the return to baseline that has been documented elsewhere. In 2 studies, physical component scores which had initially decreased after donation had returned to normal by 4 months (Kroencke et al., 2012) and 12 months (Bahler and Sundaram, 2013, García et al., 2013). The failure of the donors in this study to return to baseline may be due the presence of co-morbidities and complications, which are not mentioned extensively in the studies cited above, or may be due to mean donor age which is 5 years higher in this sample.
**Self-esteem**

Prior to this study, self-esteem in living kidney donors had been measured prospectively in 3 studies (Simmons and Anderson, 1982, Virzi et al., 2007, Garcia et al., 2013), only 1 of which had used a validated measure (the Rosenberg scale) (Simmons and Anderson, 1982). The study by Simmons and Anderson demonstrated that at 5-8 years after donation, self-esteem increased in 51% of donors, stayed the same in 21% and decreased in 28%. This study is the first to report pre-operative, 3 and 12 month self-esteem scores and an increase in self-esteem was not demonstrated. On the donation-specific questions a large number of donors reported that living donation had increased their self-esteem, despite their being no corresponding increase in scores on the Rosenberg self-esteem questionnaire.

The reasons for this are unclear but may possibly be related to time. As noted above, the majority of donors whose self-esteem was measured at 5 years demonstrated an increase when compared to pre-operative scores. It may be that donors feel that their self-esteem has increased at 12 months, however it may take longer for it to manifest as a change in Rosenberg scores. Another reason could be that donors may think that their self-esteem has improved when in reality it has not, or that it was artificially elevated in the immediate pre-operative period and is therefore not a true baseline score. It is also possible that a donor may misinterpret the positive emotions of having donated a kidney as an increase in self-esteem, when in fact they are experiencing another emotion altogether. As with previous studies, factors associated with an increase in self-esteem were not identified from this study.

**Regret**

The level of regret in this study (defined as those who agree or strongly agree to the question “If I had my time again I would not choose to be a Living Kidney Donor”) was 6.8% at 3 months and 10.7% at 12 months, which fell within the range of regret reported in the review by Clemens and colleagues (0-17%). Previously documented risk factors for regret, such as graft loss and complications, were not elicited from this study because the numbers of donors demonstrating regret, and the number of recipients who had died or lost their grafts, were both very small and therefore accurate and appropriate statistical analyses were not possible.
Social factors
This study is the first to use validated questionnaires to prospectively measure social support and social comparison in living kidney donors. A minority of prospective studies attempting to measure social factors have not used validated measures but have instead used self-designed question to measure post-operative donor-recipient relationships and donors’ relationships with others (Simmons and Anderson, 1982, Lumsdaine et al., 2005, Minz et al., 2005, Garcia et al., 2013).

In this study, 81.7% of donors at 3 months and 89.6% of donors at 12 months felt that their relationship with their recipient was either the same or better than prior to the transplant. At 3 months these figures are lower than the range reported in the review by Clemens et al (86-100%) and at 12 months are just within range. The more conservative rates reported from this study are likely to be more accurate than those reported in the review by Clemens and colleagues, given that they were measured prospectively.

A slightly higher proportion of donors felt that their relationship with others around them was the same or had improved after donation (88.6% at 3 months and 87.3% at 12 months). Contradicting these findings was the statistically significant decrease in social support scores at 12 months. This was an unexpected finding, given that so many donors felt that their relationships with others had either stayed the same or had improved. It is not possible to say whether the pre-operative average score was the donors’ true baseline social support score or whether this was artificially inflated within the pre-operative period; given that the donor was about to undergo surgery and may have additional support measures in place. If this was the case, the reduction in scores over the first year may simply reflect a return to baseline. If this was not the case, the decrease in scores may be due to a true reduction in social support which occurred because those within the donor’s social network may have felt that their pre-operative level of social support was no longer required once the transplant had taken place and the recipient was better.

This study demonstrated in 8% of cases, the relationship between donors and their recipients had deteriorated within the first year after transplantation. The reasons for the relationship worsening was not always clear, but in some cases were directly related to the transplant. Reasons included unmet expectations of what the recipient would do with their life after transplantation and a reduction in contact after the
transplant had taken place. Some relationships had completely broken down for reasons that were unclear from the research questionnaire, however direct communication with the donors and interrogation of the Electronic Patient Record (EPR) system did reveal some possible causes. These included financial difficulties and marital problems that were present before the transplant had taken place. The financial burden of donation was not formally assessed as part of this study but has previously been found to be an extreme or large burden in up to 62% of cases (Zhao et al., 2010). There are no available data that have measured donor-recipient relationships before and after donation, so it is unclear whether the rate of relationship decline demonstrated here is less or greater than average. Additionally the numbers of donors experiencing recipient relationship difficulties was too small to conduct a formal analysis alongside the questionnaire data that was obtained.

Section 2 - Other
Despite there being no clinically significant improvement in scores across any of the validated questionnaires, some post-operative benefits were obtained from the donation-specific questions, many of which were consistent with the themes outlined in the thematic synthesis performed by Tong and colleagues, as discussed in chapter 2 (Tong et al., 2012a). Pre-operatively, increased personal benefit was anticipated by few donors; however improvement in quality of life for both parties was a particular anticipated benefit for spousal donors. Positive outcomes after living donation from the thematic synthesis included a new appreciation of life, a more positive outlook for the future and that life was more valuable. Tong and colleagues also found that donation increased self-worth, confidence and that donors were praised, given ‘hero status’ and received recognition for their donation. This study also demonstrated that of all the different donor-recipient relationships, spousal donors had the greatest expectation of personal benefit following living kidney donation. This study also demonstrated that the majority of donors felt that donation was one of the best things they had ever done and that they felt good about being a living donor. In this study large numbers of donors had been praised for donating a kidney, felt that their outlook on life had changed, and that their self-esteem had improved.

It seems extraordinary that so many donors demonstrated a benefit across the donation-specific questionnaires, whilst demonstrating no benefit across the validated psychosocial questionnaires. Possible reasons behind this may be that the wrong
Section 3

Section 3 of the study corresponded to the third hypothesis, which stated that psychosocial wellbeing of a subset of donors would improve after donation and a subset would decline. More specifically, hypotheses 3.1 stated that primary caregivers and parents would demonstrate an improvement in scores 12 months after donation. Hypothesis 3.2 stated that the following groups would demonstrate a decline after donation: donors who had experienced post-operative complications, donors whose recipients had died or lost their kidney within the study period, donors whose recipients experienced post-operative complications and donors whose relationships with their recipient or others around them had deteriorated since the donation took place.

Hypothesis 3.1

This study demonstrated that primary caregivers and parental donors had worse pre-operative questionnaire scores across a range of measures. These were shown to improve at 3 months, however this was not sustained to 12 months. This meant that the pre-operative differences between parental donors and non-parental donors, and primary caregivers and non-primary caregivers, were also present at 12 months. In both the parental donor and primary caregiver groups the only psychological measure which demonstrated a sustained improvement at 12 months was wellbeing, however there was no statistically significant difference between pre-operative and 12 month scores.

In the more short term recovery period, primary caregivers reported taking longer to return to normal than non-primary caregivers (9.1 weeks vs. 6.8 weeks). This is likely to be due to the issue of multiplicity of roles; that is, the primary caregiver group must not only recover from their own operation but must also care for their recipient at the same time. This concept has been documented on previous occasions within the qualitative living donor literature and consequently became a subtheme within the qualitative synthesis of donor motivations and experiences published by Tong and colleagues (Tong et al., 2012a). This qualitative synthesis of 26 studies demonstrated that for some family donors, contending with multiple roles after donation was
challenging, stressful and had a negative impact on recovery. The results reported in this study provide quantitative data in support of these qualitative findings.

The initial improvement in scores in both the primary caregiver and parental donor groups may reflect an initial post-transplant euphoria associated with a dramatic improvement in quality of life. Both primary caregivers and parents are likely to have benefitted more from the drastic improvement in the recipient’s health, which often occurs immediately after transplantation. This may be due to a reduction in caregiver responsibilities or may reflect the fact that the source of pre-operative psychological distress has been removed or treated.

When reflecting on why so many psychosocial factors demonstrated no sustained improvement over the first year after donation and why primary caregiver and parental donor scores returned to their pre-operative baseline at 12 months, a possible explanation can be found in “Expectations of the Process” part of the qualitative study. Within this section donors commented on how they had realised over time that transplantation provided no ‘quick fix’ for renal failure and that renal disease would always play a part in theirs and their recipient's lives. Pre-operatively donors had focussed on the misery associated with renal disease and had mainly worried about whether the transplant would go ahead and whether the kidney would work. It is likely that many donors had not contemplated what life would be like after the transplant had taken place. The realities of living with someone with a transplant include an ongoing threat of transplant failure and life-threatening complications. This is likely to be something that had not been considered in the pre-operative period and only occurred to donors after their recipient had survived their transplant operation and settled into their post-transplant routine.

**Hypothesis 3.2**

Having a complication, readmission to hospital and the need for surgery for complications were not associated with statistically significant differences in any of the psychosocial questionnaires pre-operatively, or at 3 or 12 months. These findings were not in keeping with other studies which have demonstrated decreased post-operative health-related quality of life and increased regret in those experiencing a post-operative complication (Johnson et al., 1999, Mjoen et al., 2011). Given that both of these studies had significantly larger sample sizes than this study (524 donors and 1414 donors, respectively) it is possible that this study had insufficient power to detect
negative outcomes. A possible explanation for the findings demonstrated in this study could be that, for the majority, the complications following living kidney donation are primarily short term and are fully resolved by 3 months. Therefore it is unlikely that a difference would be demonstrated on the 3 month questionnaire, unless the medical or surgical issues were ongoing. Another explanation may be that having a complication is of little relevance or significance to the donor, given that their recipient is most likely to be enjoying better health and a much improved quality of life.

Study strengths
A major strength of this study was the very low refusal rate (4.6%), which meant that the sample included donors across of different ages and ethnicities, and donors with different social and religious backgrounds. A variety of different donor-recipient relationships were also included. Due to the high recruitment rate the sample was closely representative of the living donor programme at Guy's Hospital, which in turn reflected the ethnic and cultural diversity of the local population. The high recruitment rate may also be an indication of a feeling amongst living kidney donors that research into the psychosocial aspects of donation is necessary. This may demonstrate that these donors’ own questions related to the psychosocial aspects of their donation had not been answered during their pre-operative living donor workup. In not having access to this information, the desire to participate in this research study not only acknowledges that this information is missing but also that it would be of help to others. In addition, this latter point may in itself be a reflection of how difficult the experience of having a loved one with renal failure has been and a desire to make it easier for future donors.

Another strength of the study was the prospective, longitudinal design, which meant that it was possible to look for changes pre-operative and post-operative scores over the first 12 months after donation. The study was relatively large in comparison to other longitudinal studies into psychosocial outcomes in living kidney donors that have been published elsewhere and is by far the most comprehensive longitudinal assessment that has ever been attempted.

Study limitations
A limitation of this study is it did not have adequate statistical power to sufficiently analyse negative outcomes such as regret, recipient death and recipient graft loss. A further limitation was the proportion of participants who failed to complete at least 1
post-operative questionnaire. Despite best efforts it has not been possible to elicit their reasons for not completing the post-operative questionnaires. It was not possible to include non-English speakers in the study (3 donors) due to the complexity of the questionnaire and the possibility of miscommunication or misinterpretation of questions and answers when obtained through an interpreter. Although these donors make up a small proportion of the annual donor sample for Guy’s Hospital (2.6%) they may represent a group of donors who are potentially vulnerable due to the language barrier. For the same reasons that they were not included in the study they may also be less likely to be referred for psychological assessment or have their mental health history elicited pre-operatively.

**Future work**

As identified in the discussion above, it is possible that the lack of benefit demonstrated in this study may be due to the relatively short amount of time over which data were collected. Pre-operatively, the living donor workup process is likely to have taken between 6-12 months, if not longer, and it is uncertain whether the psychosocial questionnaire scores given 2-4 weeks before surgery represent a true baseline. Similarly, the benefits of living donation are also likely to last well beyond the 12 month anniversary of the donation. Future work should attempt to include questionnaire time points across the entire living donor workup period and further into the post-operative period; for example, 5-10 years.

The other consideration that is worth investigating is the psychosocial impact on those who do not successfully make it through the living donor workup process and who therefore are unable to donate. Whilst this study has failed to quantitatively demonstrate a psychosocial benefit from living donation, it has also failed to quantitatively demonstrate harm. A future study may wish to include all individuals who initially present to a transplant centre as a potential donor and then follow up both those who go on to donate and those who do not. If a psychosocial harm is demonstrated by not allowing an individual to donate, it may be that transplant professionals are forced to consider this as part of their decision making process and their assessment of harm versus benefit to both the donor and the recipient.

**Summary**

The main finding of this study is that it has not been possible to demonstrate a sustained improvement in psychosocial questionnaire scores after living kidney
donation. This is despite donors subjectively reporting that they felt good about donating, that their outlook on life had changed and their self-esteem had improved. Pre-operative scores in parental and primary caregiver groups were found to be worse across a number of measures and these persist at 12 months, despite an improvement in the short term. This means that these 2 groups remain psychosocially disadvantaged both pre- and post-operatively.

The reasons for a lack of improvement in scores after living donation are not clear. The most likely explanation is that although a living donor may have helped their recipient through the gift of a kidney transplant, it is a mode of treatment for a chronic condition rather than a cure. Although quality of life improvements are likely to result from transplantation, the ongoing possibility of complications, graft failure and premature recipient death still persist and provide an ongoing cause of concern.
Chapter 6
Stress, Personality and Wound Healing in Living Kidney Donors

Introduction
Psychological stress has been shown to be an influential factor on the rate of wound healing in different parts of the body, in different clinical circumstances and through the use of different modalities (Gouin and Kiecolt-Glaser, 2011). A wound is defined as a disruption of normal anatomical structure and function (Lazarus et al., 1994) and healing of any wound necessitates progression through an overlapping step-wise process in which a variety of different inflammatory mediators facilitate repair to the damaged area. There are four stages of cutaneous wound healing: vascular, inflammatory, proliferative and maturation (Black and Matassarin-Jacobs, 1997).

The vascular stage commences within seconds of the injury with the constriction of blood vessels within the damaged area, which in turn reduces the blood flow to the wound. Platelets then gather to form a fibrin clot. The inflammatory phase, usually characterised by swelling, heat, pain and loss of function, involves the infiltration of a large number of different immune cells to the wound site. These ingest bacteria and debris within the wound, thereby preparing the site for the proliferative phase. These cells also release cytokines, such as interleukin-1 (IL-1α, IL-1β), IL-6, IL-8, tumour necrosis factor alpha (TNF-α) and other inflammatory mediators, which, through their chemo-attractant properties, help recruitment and migration of necessary cells to the wound area (Kiecolt-Glaser et al., 1995). The proliferative phase, which most commonly starts four days after the initial injury, then commences. This phase involves the deposition of collagen, angiogenesis (the formation of new blood vessels), granulation (where the space wound space is filled with new tissue) and wound contraction (Black and Matassarin-Jacobs, 1997). Epithelial cells migrate into the wound from neighbouring skin, which in turn facilitates the skin to regrow. These cells then differentiate into the different layers of the epidermis and an initial scar is formed.

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3To note, this chapter has been published in: Maple H, Chilcot J, Lee V, Simmonds S, Weinman J, Mamode N. Stress predicts the trajectory of wound healing in living kidney donors as measured by high-resolution ultrasound. Brain Behav Immun. 2015 Jan;43C: 19-26
The maturation phase, which involves remodelling of the initial scar, continues for many months afterwards and results in scar tissue formation.

It is evident from the different stages of the wound healing process that wound healing is dependent on a broad range of internal and external factors, one of which is a fully functional immune system that is able to respond appropriately to tissue injury (Walburn et al., 2009). It is through the immunological pathway that stress is thought to have a modulatory influence (Segerstrom and Miller, 2004) via activation of the hypothalamic-pituitary-adrenal axis and the sympathetic-adrenal-medullary axis. It is also recognised that stress can have significant behavioural effects, for example on diet (Torres and Nowson, 2007) and sleep (Ohayon, 2009), which, in turn, affect the speed of wound healing.

Although the link between psychological stress and healing is well established, there are few studies that have evaluated cutaneous surgical wounds (Holden-Lund, 1988, Scheier et al, 1999, Broadbent et al., 2003, Doering et al., 2005, Broadbent et al., 2012). These studies have demonstrated that increased psychological stress is associated with an increase in wound complications, such as infection (Doering et al., 2005, Scheier et al, 1999), and reduced levels of inflammatory markers, such as interleukin-1 (IL-1) and metalloproteinase-9 (MMP-9) (Broadbent et al., 2003). Randomised studies of psychological interventions that aim to minimise stress in surgical patients, such as Relaxation with Guided Imagery (RGI) and expressive writing, have demonstrated an improvement in wound healing in the intervention group (Holden-Lund, 1988, Weinman et al, 2008, Broadbent et al, 2012, Koschwanez et al, 2013).

In addition to stress, personality has also been shown to impact upon health outcomes, both directly through physiological mechanisms and indirectly through patient behaviour. Conscientiousness is thought to lead to a healthier, longer life through the collective reduction of many small risks, which result from conscientious behaviour (Friedman and Kern, 2014). Further, highly conscientious individuals report fewer daily stresses (O’Connor et al., 2009) and engage in more adaptive coping styles (Grant and Langan-Fox, 2006, Kern and Friedman, 2008), suggesting that personality may moderate the potentially damaging effects of stress, which has been referred to as the stress moderation model (Weihe et al, 2010). Lower levels of optimism have been associated with slower wound healing (Ebrecht et al., 2004) and an increase in wound infection and all-cause rehospitalisation after coronary artery bypass graft surgery.
Combinations of personality traits have also been demonstrated as being particularly harmful, such as a low level of conscientiousness coupled with high neuroticism, which leaves an individual at high risk of poor health outcomes (Friedman and Kern, 2014).

The quantitative study described in chapters 4 and 5 provided a rare and unique opportunity to examine the association between stress and surgical wound healing for two reasons. Firstly, living kidney donors are patients who, prior to surgery, are extensively screened for underlying pathology and are only allowed to donate if fit. They should therefore be free from all major physical and psychological co-morbidities that may directly affect wound healing. Secondly, they are healthy but undergo major surgery for the benefit of another individual, with no physical benefits to themselves. It is therefore crucial that the physical trauma of surgery is minimised and that they recover quickly from the procedure with few complications.

The aim of this study was to evaluate the trajectory of wound healing in living kidney donors using high-resolution ultrasound, and to ascertain which potentially modifiable factors predict recovery. High resolution ultrasound (HRUS) was the chosen modality to assess wound healing because it provides an objective, reliable, non-invasive method of quantitatively assessing structural changes deep within a wound that correlates highly with tissue histology, photography and nuclear magnetic resonance spectroscopy (Dyson et al., 2003, Harland et al., 1993, Hu et al., 1998, Rippon et al., 1998). The HRUS machine provides a detailed image of the different layers of the skin, through which the size of the wound and differences in the fluid content can be measured. HRUS has been used on one previous occasion to investigate the association between wound healing and stress (Ebrecht et al., 2004) and although the use of HRUS to measure skin tissue fluid content has not previously been used in psychological research, it has been extensively validated in other studies (Gniadecka et al., 1994, Seidenari and Di Nardo, 1992a, Seidenari and Di Nardo, 1992b, Gniadecka, 1995).

The hypothesis of this study was that pre-operative life stress would predict the trajectory of wound healing. Given the prediction of the stress-moderation model, optimism and the 'big five' personality factors were also explored along with the interaction between stress and personality, to determine whether these factors were also predictive of wound healing.
Methods

Sample

As detailed in the longitudinal study outlined in chapters 4 and 5, participants were living kidney donors who donated at Guy’s Hospital, London between August 2012 and August 2013. A subsample of donors from the same cohort consented to having their surgical wounds scanned with the HRUS machine during their hospital admission (days 1, 2 and 3) and at their follow up appointment 2-3 weeks after surgery. NHS research ethics approval was obtained (09-H0804-31). As before, donors were approached by a researcher on one occasion, two to four weeks prior to scheduled surgery following completion of all medical tests and appointments. Questionnaires were completed 1-4 weeks prior to surgery. The following scales were analysed against the wound healing data: the 4-item Perceived Stress Scale (PSS) (Cohen et al., 1983), The Big Five Personality Inventory (10-item) (Gosling et al., 2003) and the Life Orientation Test – Revised (LOT-R) (10-item) (Scheier et al., 1994).

Surgical and hospital procedure

Donors were admitted to hospital on the day of surgery and underwent their procedure on an elective operating list by a consultant transplant surgeon. The centre uses a hand-assisted laparoscopic technique, which is a modified form of keyhole surgery. The patient is left with three wounds after their operation (Figure 6.1). The largest is the ‘hand-port’ which is a vertical or horizontal wound located in the midline of the abdomen, either above or below the umbilicus. This provides access for the surgeon’s hand during the operation and is the extraction site for the kidney. This wound is 7-10cm in length and is the largest of the three. Two smaller wounds (5-10mm) are used for the laparoscopic instruments and the camera. For continuity, all donors received the same skin closure (3/0 subcutaneous Monocryl®) and the same dressing. In order to facilitate wound scanning, surgical glue (Dermabond®) was applied as an alternative to an opaque adhesive dressing. A subcutaneous wound drain (which sits in the fatty layer just beneath the skin) was inserted into the hand-port wound at the surgeon’s discretion.

Donors were visited on the first three post-operative days whilst they were in hospital (day 1 being the day after surgery). Visits were made in the mornings at the same time each day to ensure 24 hours had passed between scans. The scans took place prior to the morning ward round in order not to disrupt the ward team. The hand-port wound was scanned during each visit. Following discharge donors were seen in the outpatient
10-20 days after their operation, at which point the same wounds were scanned for the final time. All scans for each subject were conducted by the same researcher to reduce inconsistency in scanning techniques. Routine blood tests including full blood count, renal and liver profile and C-reactive protein (CRP) were collected at baseline and at follow up from the hospital Electronic Patient Record (EPR).

Figure 6.1: Possible wound sites for Hand-assisted Laparoscopic Donor Nephrectomy

**Image capture**

All wounds were scanned using the Episcan© I-200 High-Resolution Ultrasound machine and a hand-held 20MHz probe. The images were recorded, at later analysed, with Episcan imaging software (version 4.0-I)(Longport International Ltd, 2007). To obtain an image the abdomen was exposed and ultrasound gel placed on the wound, on top of the glue dressing. This ensured that the wound was not directly exposed to the ultrasound probe, thereby minimising the risk of infection. The probe was placed on top of the ultrasound gel, pressed gently onto the wound and moved until a cross-sectional image was displayed on the screen. The image was then captured and the process repeated until the researcher was confident that at least one good quality image had been obtained. The final position of scanning on the wound was documented to ensure consistency with the scans performed on subsequent days. The same area was scanned in the same manner at all four time points by the same person. Additional researchers included two medical students intercalating their medical
degree with BSc in health psychology and an MSc health psychology student. These students performed scans on the final 20 patients and participated in the analysis of the images.

**Image analysis**

For each donor, the best quality image at each time point was selected (four images from days 1-3 and follow-up). The wound area is easily identifiable on the image as an area of black (a reflection of the increased fluid content) located immediately beneath a break in the epidermis (Figure 6.2). Figure 6.3 provides an image of normal skin for comparison. The first 3 millimetres (mm) beneath the epidermis was used for analysis as this was the most consistent area of skin between patients and was the part least affected by Body Mass Index (BMI). Image analysis started with the images taken on day 1. A 3mm line was dropped from beneath the epidermis in the centre of the wound. A “wound area” box was then drawn around it to represent the wound area (Figure 6.4). The width of the wound (WW) was measured as the width of the box and an additional measurement (median intensity (MI)) was also taken (Figure 6.5).

MI is a reading produced by the Episcan® imaging software and reflects the amount of tissue oedema (swelling) in the defined area. Post-operative oedema is part of the inflammatory stage of wound healing, whereby the area in and around the surgical wound is infiltrated with tissue fluid. It is reflected by a lower MI score reading, which will subsequently increase as the fluid is absorbed and the tissue heals. The advantage of using MI is that it quantifies the microscopic changes in tissue structure and oedema content over time, and these changes are not always visible to the naked eye.

Once both WW and MI measurements had been taken for the day 1 image, the box was copied onto the centre of the image selected for day 2. WW was calculated by drawing a horizontal line over the widest part of the wound, which may have been greater or less than the width of the wound on day 1. Median intensity was similarly calculated using the same box area so a comparison could be made between days 1 and 2. This process was repeated for day 3 and for the follow up images. The total number of readings per wound was 8: 1 wound width and 1 median intensity measurement for each time point (days 1-3 and follow up).
Figure 6.2 - Episcan wound image suitable for analysis. Three distinct layers are visible – the ultrasound gel (above the wound), the epidermis (green layer) and the dermis. The wound area is visible in the centre of the picture with a central peak (corresponding to the suture line) and an area of low pixilation underneath (the wound area), which corresponds to an increase in fluid content.
Figure 6.3 – Normal skin
Figure 6.4 - A 3mm line is dropped onto the image from the top of the wound. A box is drawn around it to represent the wound area.
Figure 6.5 - A horizontal line is drawn across the width of the box to represent wound width (WW). A median intensity reading (MI) for the box area is calculated by the Episcan© machine software.
Reliability

The images were analysed independently by two researchers on separate days. This was to increase validity and avoid researcher bias. Additional steps to reduce bias included anonymising the data and blinding the researchers to the questionnaire scores. Inter-rater reliability was examined to ensure that the wound assessment method was effective. A Pearson correlation was performed to determine the level of agreement between the two researchers. All correlated highly ($r > 0.8$, $p < 0.05$), thereby demonstrating consistency between both researchers. For the main statistical analysis, the averages (mean) in wound measurements from both sets of data were used.

Statistical analysis

Latent Growth Curve Models (LGCM) were used to evaluate wound healing over approximately 2 weeks. All models were run in Mplus version 7.11 using the Robust Maximum Likelihood estimator (MLR). The models were run using the TSCORES option in Mplus, since the time in which donors were scanned at the final follow-up (time 4) varied between 10-20 days (average follow-up = 15.3; SD= 0.8). This particular kind of growth model uses the actual time of the follow-up (days 1, 2 and 3 were fixed accordingly; the actual time of the final follow-up was included in the model). Unconditional univariate LGCMs for both MI and WW were first evaluated. Linear and non-linear models were evaluated (data not shown). For both MI and WW, linear change models were the most appropriate, showing good model fit based upon Akaike (AIC) and Bayesian information criteria (BIC). Since MI measures tissue oedema, a conditional LGCM was then examined, which controlled for whether a post-operative wound drain was inserted (dummy coded variable). Further conditional LGCMs for both MI and WW were ran in order to evaluate the effect of stress and personality on wound healing. This was achieved by regressing the intercept and slope of the respective wound healing models (MI and WW), onto the predictor variables (stress, personality and stress-personality interactions). Interactions were modelled using centred means.

Since the growth models used TSCORES, convention model fit criteria (e.g. the Comparative Fit Index [CFI], Tucker Lewis Index [TLI], The Root Mean Square Error of the Approximation [RMSEA]) cannot be computed. However linear growth models examining the trajectory of both MI and WW across days 1-3 post surgery (i.e. three
fixed time points) demonstrated good fit according to these standard indices (CFI and TLI >0.92; RMSEA<0.08).

**Results**

**Sample Characteristics**

A consecutive sample of fifty-eight donors consented to and participated in the study. Six were excluded from the analysis due to their follow up appointment taking place at 4-6 weeks after discharge rather than 2-3 weeks. This left 52 patients for analysis. The average time between patients completing the preoperative questionnaires and the day of the donation was 12.2 days ($SD = 5.6$). Demographic and clinical details are provided in Table 6.1. Forty-three donors (82.7%) had no medical or psychiatric issues requiring medication at the time of donation. Nine donors were medicated for one or more of the following medical problems: hypertension, hypothyroidism, hyperthyroidism, asthma, hypercholesterolaemia and gastro-oesophageal reflux disease. Six donors (11.5%) had a previous history of a mental health condition, including depression (5 donors) and Post-Traumatic Stress Disorder (PTSD) (1 donor). Eight donors (15.4%) had an active mental health condition including depression requiring medications (4 donors), anxiety disorder (1 donor), mixed anxiety and depression (2 donors) and stress (1 donor). The mean stress and optimism scores were 4.78 ($SD = 2.6$) and 20.2 ($SD = 6.5$) respectively. Mean scores on the big five personality domains were as follows: Extraversion 9.1 ($SD = 3.2$), Agreeableness 10.0 ($SD = 2.3$), Conscientiousness 11.3 ($SD = 2.4$), Openness 10.3 ($SD = 2.4$) and Emotional Stability 9.8 ($SD = 2.96$). As expected, patients’ preoperative bloods were unremarkable. C-Reactive Protein (CRP) values for 3 donors were marginally above the normal range (>5 mg/L), however these findings were not clinically significant. The most common type of donation was parent to child (N=21, 40.3%). Local anaesthetic was used in 33 donors (63.5%) and a wound drain inserted into 11 (21.1%). The average length of stay was 4 days (minimum = 2 days; maximum = 7 days) and the average time between discharge and follow up was 15.3 days ($SD = 2.8$).
### Table 6.1: Demographic and clinical data (N=52)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
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<tr>
<td>Male</td>
<td>29 (55.8%)</td>
</tr>
<tr>
<td>Female</td>
<td>23 (44.2%)</td>
</tr>
<tr>
<td>Mean age at donation (years, SD)</td>
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</tr>
<tr>
<td>Donor-Recipient Relationship</td>
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<tr>
<td>Parent to child (&lt;18)</td>
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</tr>
<tr>
<td>Parent to child (&gt;18)</td>
<td>11 (21.2%)</td>
</tr>
<tr>
<td>Spouses</td>
<td>10 (19.2%)</td>
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<tr>
<td>Siblings</td>
<td>5 (9.6%)</td>
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<tr>
<td>Child to Parent</td>
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<tr>
<td>Distant Relatives</td>
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<tr>
<td>Friends</td>
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<tr>
<td>Altruistic Donor</td>
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<tr>
<td>Ethnicity</td>
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<tr>
<td>White</td>
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</tr>
<tr>
<td>Non-white</td>
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</tr>
<tr>
<td>Smoking status</td>
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<tr>
<td>Current smoker</td>
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<tr>
<td>Non-smoker</td>
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<tr>
<td>BMI (mean, SD)</td>
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<tr>
<td>Pre-operative Blood results (mean, SD)</td>
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<tr>
<td>Haemoglobin (g/dL)</td>
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<tr>
<td>Female</td>
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<td>Albumin (g/L)</td>
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<tr>
<td>eGFR (mL/min)</td>
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<tr>
<td>CRP (mg/L)</td>
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<tr>
<td>&lt; 5 (not inflamed)</td>
<td>49 (94.2%)</td>
</tr>
<tr>
<td>&gt; 5 (inflamed)</td>
<td>3 (5.8%)</td>
</tr>
<tr>
<td>(Range: 5-9 mg/L)</td>
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</tr>
</tbody>
</table>
Image characteristics

The mean wound width and median intensity scores are provided in Table 6.2. As expected, the wound width decreases and the median intensity score increases over time, which reflects the wound healing process. A median intensity score for normal skin is provided as a point of reference and this was obtained by scanning an area of normal skin located separately to the surgical wound on day 1. The median intensity value was obtained by copying the same box area used on the other images for that donor. Unsuitability of the hand-port wound for scanning accounted for missing data (day 1= 2%, day 2= 6%, day 3=8%, follow-up=8%). Wounds were not scanned when the dressing had leaked, where there was a break in the skin, or evidence of infection (erythema and swelling of the wound) since this would increase the risk of introducing further infection and would limit the quality of image obtained.

Table 6.2: Image data for each time point (Mean and SD)

<table>
<thead>
<tr>
<th></th>
<th>Day 1</th>
<th>Day 2</th>
<th>Day 3</th>
<th>Follow-up</th>
<th>Normal skin</th>
</tr>
</thead>
<tbody>
<tr>
<td>n</td>
<td>49</td>
<td>47</td>
<td>47</td>
<td>47</td>
<td>50</td>
</tr>
<tr>
<td>Wound Width (mm)</td>
<td>6.92 (1.98)</td>
<td>6.12 (1.84)</td>
<td>5.85 (1.78)</td>
<td>4.90 (1.99)</td>
<td>-</td>
</tr>
<tr>
<td>Median Intensity</td>
<td>6.71 (1.83)</td>
<td>7.35 (2.03)</td>
<td>7.42 (2.05)</td>
<td>10.15 (3.76)</td>
<td>19.6 (4.16)</td>
</tr>
</tbody>
</table>

Correlates of preoperative stress at baseline

Preoperative life stress was unrelated to age, gender, smoking status, preoperative serum haemoglobin, serum albumin, estimated Glomerular Filtration Rate (eGFR), C-reactive protein, body mass index and length of hospital stay (effect sizes between 0.01 to 0.20, p values >0.05). In addition preoperative stress was not associated with the number of days between completing the stress measure and date of the surgery (r=-0.13, p=0.40 – Independent samples T-test). Mean stress scores were significantly higher in individuals donating to a child compared to a friend or other relative (mean difference = 1.6, [95% CI 0.26 and 3.1], p=0.02). Stress scores correlated significantly and negatively with optimism (r=-0.67, p<0.01) conscientiousness (r=-0.36, p=0.01) and emotional stability (r=-0.53, p=<0.01), but were unrelated to extraversion, openness to experience and agreeableness.
**LGCM: trajectory of wound healing as measured by median wound intensity.**

A LGCM for MI was run (AIC=791.1; BIC= 808.4; number of free parameters=9). Specifically, both the intercept and slope was significant (Table 6.3), although the variance in the change over time (slope [days]) was non-significant. The mean change in the slope was 0.22 ($p<0.01$), indicating that per unit of time, MI was increasing significantly by 0.22 units. Since the longitudinal evaluation of MI could be influenced by the insertion of a wound drain, a conditional growth model was evaluated which controlled for wound drain use (dummy coded variable correlated with both the intercept and the slope). This conditional growth model had a slightly better fit than the unconditional model, evidenced by a reduction in both the AIC and BIC (AIC=727.3; BIC= 747.7; number of free parameters=11) so this was used in subsequent analysis. Both mean intercept and slope factors were significant (Table 6.3). Wound drain was significantly associated with the intercept mean (beta=1.7, $p<0.01$) but not with the slope.

**LGCM: trajectory of wound healing as measured by wound width.**

A LGCM model for wound width showed similar findings to the MI models, with comparable model fit (AIC=719.1; BIC= 736.3; number of free parameters=9). Both the intercept and slope factors were significant (Table 6.3). Per unit of time, wound width reduced by 0.10 units (mm).

<table>
<thead>
<tr>
<th>Table 6.3: Summary of growth models examining the trajectory of wound healing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Estimate (standard error)</td>
</tr>
<tr>
<td>Intercept Mean</td>
</tr>
<tr>
<td>-----------------</td>
</tr>
<tr>
<td>Median Intensity</td>
</tr>
<tr>
<td>Median Intensity (conditional)*</td>
</tr>
<tr>
<td>Wound Width (mm)</td>
</tr>
</tbody>
</table>

*a controlling for wound drain insertion. Modelled using T scores.

**p<0.01
Predictors of the rate of wound healing

A summary of stress and personality factors as predictors of the intercept and slope (change) for both MI and WW are shown in Table 6.4. Stress significantly predicted the rate of wound healing for both MI and WW. A point increase in stress at baseline was associated with a 0.03 decrease in the change of MI per unit of time \((p<0.01)\) and 0.02 increase in WW per unit of time \((p<0.01)\). Conscientiousness and optimism also significantly predicted the slopes in both MI and WW models (Table 6.4), suggesting that higher levels of both constructs were associated with quicker rates of wound healing. Emotional stability was associated with the change in MI \((\beta=0.02, p<0.01)\), but not WW \((\beta=-0.07, p=0.09)\).

Exploring the interaction of stress and personality upon wound healing

Since stress, optimism and conscientiousness predicted the change (i.e. the slope) of wound healing as measured by MI and WW, the interaction between personality and stress was tested in subsequent LGCMs. Two models were evaluated testing the interaction between stress and conscientiousness and stress and optimism (using centred means). In both models, the interaction term \(((\text{stress} \times \text{personality}) / (\text{optimism or conscientiousness}))\) was specified to predict the intercept and the slope factors for both MI and WW. For both measures of wound healing, the interaction between personality and stress was not associated with the rate of wound healing \((p>0.05)\). Conscientiousness however, remained a significant predictor of the change (slope) for both MI and WW (MI; \(\beta=0.02\); WW \(\beta=-0.17, p<0.05\)), although the effect of stress in both models became non-significant.

Table 6.4: Psychological predictors of wound healing

<table>
<thead>
<tr>
<th>Models</th>
<th>MI</th>
<th>WW</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Intercept</td>
<td>Slope</td>
</tr>
<tr>
<td>Stress</td>
<td>0.06</td>
<td>-0.03**</td>
</tr>
<tr>
<td>Optimism</td>
<td>-2.1</td>
<td>0.61**</td>
</tr>
<tr>
<td>Extraversion</td>
<td>-0.04</td>
<td>0.01</td>
</tr>
<tr>
<td>Conscientiousness</td>
<td>-0.05</td>
<td>0.02**</td>
</tr>
<tr>
<td>Openness</td>
<td>-0.01</td>
<td>0.01</td>
</tr>
<tr>
<td>Agreeableness</td>
<td>0.30**</td>
<td>0.01</td>
</tr>
<tr>
<td>Emotional Stability</td>
<td>0.03</td>
<td>0.02**</td>
</tr>
</tbody>
</table>

*p<0.05 Unstandardized estimates
**p<0.01
**Discussion**

This is the first study to examine the relationship between pre-operative psychological factors and wound healing in living kidney donors. The findings demonstrate that increased psychological stress prior to surgery is associated with delayed wound healing in living kidney donors across two separate markers: wound width (size) and median intensity (level of tissue oedema / swelling), supporting the primary hypothesis. Furthermore, it was found that optimism and conscientiousness predicted wound healing as measured by both wound width and median intensity, and increased emotional stability was associated with faster wound healing, as demonstrated by a change in median intensity. Possible confounding factors, such as age, BMI, smoking status, the use of local anaesthetic and placement of a subcutaneous wound drain were not found to be influential. The main strengths of this study lie in the use of a genuine surgical wound with which to assess wound healing, the use of two separate ultrasonographic markers, one of which (median intensity) has not previously been used in this field, and the unique patient sample. With regards to the later, unlike other surgical wound healing studies, our patients were free from significant physical or psychological co-morbidities since they were healthy donors. Accordingly, the potential of confounding due to variation in underlying health issues is minimal, and thus provided a novel surgical group to examine wound healing.

The association between increased pre-operative stress and delayed wound healing is not a new phenomenon with other studies demonstrating an association using a variety of different techniques, both in animal and human experiments (Kiecolt-Glaser et al., 1995, Marucha et al., 1998, Padgett et al., 1998). High-resolution ultrasound is a relatively novel way to assess cutaneous wound healing (Dyson et al., 2003) and has been used on one previous occasion to investigate the association between wound healing, stress, and optimism (Ebrecht et al., 2004). It has also been used in the assessment of renal transplant patients, but this was with the primary aim of detecting evidence of rejection within the transplant kidney rather than an assessment of the wound itself (Calvin et al., 1997). By demonstrating a slower reduction in wound width in those patients with increased stress, this study has reinforced the findings demonstrated by Ebrecht et al (2004).

In addition, this study has provided further supportive evidence in the form of an additional ultrasonographic marker of wound healing (median intensity), which has not previously been used in researching the relationship between psychological factors...
and healing. The use of an ultrasonographic method to assess wound healing is beneficial as not only does it provide quantitative data with which to make an objective assessment of the wound, it also provides information about what is taking place beneath the skin. The latter point is especially useful in surgical wounds where the epidermis is closed with a suture and a dressing applied. The additional advantage of using a median intensity reading is that it allows detection of very subtle differences within the skin which are invisible to the naked eye. The use of two independent raters with high inter-rater reliability in this study provides additional strength to the findings.

Living kidney donors are a unique group of patients on which to assess the impact of stress on wound healing as they are free from major underlying physical and psychological pathology yet they undergo major surgery. They therefore have genuine surgical wounds on which to assess wound healing without any of the potential confounding factors that may be present in an alternative surgical patient sample undergoing an operation for their own benefit, for example cancer, infection or an inflammatory process. In addition, living kidney donation is often an incredibly stressful procedure as the donor is usually undergoing surgery on the same day as a loved one. The importance of demonstrating that psychological stress as an influential factor for wound healing is that it is a modifiable factor, which may be reduced by a pre-operative psychological intervention.

There have been a number of randomised studies that have demonstrated improved wound healing after a psychological intervention, both in surgical patients and healthy individuals (Holden-Lund, 1988, Broadbent et al., 2012, Weinman et al., 2008, Koschwanez et al., 2013). Techniques have included Relaxation with Guided Imagery (RGI) (Holden-Lund, 1988, Broadbent et al., 2012) and an emotional disclosure intervention (expressive writing) (Weinman et al., 2008, Koschwanez et al., 2013). In these studies wounds have been assessed by photography, the presence of hydroxyproline within the wound (as a measure of collagen deposition) and subjective wound assessment by the Wound Assessment Inventory (WAI). Both of these interventions, which are brief and easy to administer, may provide a cost-effective way of reducing pre-operative psychological stress in this patient sample. This is especially important in this group of patients, as they are undergoing surgery for the benefit of another person and the harm inflicted by surgery ought to be kept as minimal as possible.
The effect of personality on surgical recovery is also not a new phenomenon; however the impact of personality on rates of wound healing is relatively novel. In the Ebrecht study (2004), in addition to higher stress, lower trait optimism was also found to be associated with inferior rates of wound healing. In our study lower optimism, conscientiousness and emotional stability were associated with inferior wound healing, however there was no interaction between any of these factors and stress, as would be predicted from the stress-moderation model. It is possible that reduced conscientiousness may be associated with poorer adherence to post-operative advice regarding wound care, ambulation and physical activity, and it is through this behavioural mechanism that the effect on wound healing takes effect. Donors are advised to keep their wounds protected through the use of topical dressings and to assess them for evidence of infection or inflammation at each dressing change. If evidence of infection is present they are advised to attend the hospital for a surgical review. Donors are additionally advised to ambulate slowly and to abstain from heavy lifting for 3 months. Emotionally stable patients may heal quicker for similar reasons, and additionally may have more social support, which can be helpful during the recovery process.

Limitations of this study include the variable time to follow up (10-20 days) and the measurement of stress at a single pre-operative time point. The level of donor stress may have been related to the underlying health of the recipient, and may have increased due to pain or unforeseen post-operative incidents, data which was not collected. Additional markers of stress, such as cortisol, would also have provided additional supportive evidence to the ultrasonographic findings, as well as potentially providing a further explanation behind the results. Future studies should measure stress on more than one occasion, possibly the day before surgery and at least once during the post-operative recovery period, and include high resolution ultrasonography alongside biochemical markers, such as cortisol or inflammatory cytokines, within serum or drain fluid samples (Kiecolt-Glaser et al., 1995, Marucha et al., 1998, Glaser et al., 1999, Broadbent et al., 2003, Ebrecht et al., 2004).

A further issue is the sample size, which limited the power of the growth models to detect interactions between stress and personality. Larger studies would allow more reliable evaluations of the interactions examined here. In relation to other potential predictive factors of wound healing, other cognitive, behavioural and social factors not examined here should be considered as these may also point to future targets for
intervention. A larger study would also allow an assessment of whether the relationship between stress, personality and wound healing has a clinical significance; for example, in the rate of infections, hernias and post-operative wound pain. The next phase of this research will be a multicentre randomised control trial with substantially larger numbers and will include the specified outcomes mentioned above. Different psychological interventions designed to reduce pre-operative stress will be compared against a control group of no intervention to determine not only whether a reduction in stress affects the rate of wound healing but also whether it provides a clinical benefit to the patient.

Conclusions
This study, measuring wound healing in a novel patient sample using a novel technique, has demonstrated a negative association between stress and wound healing and the positive influence of optimism, conscientiousness and emotional stability. Future wound healing research using high-resolution ultrasound should utilise the median intensity measurement to provide additional data that is not visible to the naked eye.
Chapter 7
Motives, Outcomes and Characteristics of Unspecified Kidney Donors

Introduction
Unspecified living kidney donors are individuals who donate a kidney to someone with whom they have no genetic or emotional relationship. This type of donation was legalised in the United Kingdom in 2006 and has since led to over 250 donations. Many different terms have been used for these donors including altruistic, anonymous, non-directed, “Good Samaritan” and unspecified. The Ethical, Legal, and Psychosocial Aspects of Transplantation (ELPAT) section of the European Society for Organ Transplantation has agreed on the term “unspecified kidney donation / donors” (UKD/UKDs) for these donors and the term “specified kidney donation / donors” (SKD/SKDs) for those donating to a recipient the donor knows (Dor et al., 2011). This nomenclature will be used throughout this chapter.

Globally, UKD is legal in only a minority of countries with the majority of donations taking place in the UK, the Netherlands and the United States of America. UKD is growing in popularity (Figure 7.1) and after an initial slow start by some, most UK transplant centres are now participating, albeit with broadly different numbers (Figure 7.2). Both SKD and UKD programmes are centrally co-ordinated by NHS Blood and Transplant (NHSBT) and legal authorisation for any transplant to proceed is granted by the Human Tissue Authority (HTA); a requirement of the Human Tissue Act 2004. Potential UKDs undergo the same physical evaluation as SKDs with an additional mental health assessment which, although no longer legally mandatory, remains the agreed clinical standard in the UK (British Transplantation Society, 2011).

Despite UKD being acceptable in the eyes of the public (Spital and Spital, 1988, Spital, 2001) and UKDs being applauded and praised in the national media, these donors are still approached with caution, suspicion and as a potential risk by some transplant clinicians and in the professional and academic literature (Challenor and Watts, 2013).

Figure 7.1 - Total number of unspecified donations taking place per year in the UK

Figure 7.2 - Range in the number of UKDs performed per UK transplant centre (to 31st December 2013)

Data courtesy of Lisa Burnapp at NHS Blood and Transplant

5 Data courtesy of Lisa Burnapp at NHS Blood and Transplant
For some, the concept of UKD is uncomfortable (Sharif, 2013), principally due to a presumption that a wish to donate is either a manifestation of an underlying psychopathology (Henderson et al., 2003) or a perceived lack of understanding by the donor of the risks involved. Historically, similar concerns were raised about SKDs when these programmes were in their infancy (Fellner and Schwartz, 1971). There are also concerns about subsequent regret after donation and potential negative consequences caused by a lack of contact or emotional involvement between donor and recipient (Mamode et al., 2013).

As discussed throughout the thesis, there are a number of ethical challenges inherent to living kidney donation, which are even more pronounced within the context of UKD. For living donors, the physical harms of surgery cannot be defensible by a physical benefit, because there is no physical benefit to the donor. Living donation is therefore justified on the basis of psychosocial benefit alone. To SKDs the benefits of donation may come from the act of donation itself (Massey et al., 2010) but is usually thought to be related to the resulting improvement in the recipient’s health. With UKD in the UK, the donor donates anonymously to someone on the waiting list and may never know who that person is. They consequently cannot benefit from directly seeing an improvement in the recipient’s health. Unspecified donation is therefore justified on the psychological benefits related to the act of donation alone.

When considering supportive evidence demonstrating a psychological benefit following UKD, there is very little clinical outcome data available. There is a broad literature on the concept of UKD and differing guidelines and practices from centres across the world (Adams et al., 2002, Crowley-Matoka and Switzer, 2005, Gilbert et al., 2005, Jendrisak et al., 2006). There are commentaries available on donation, altruism and the role of the psychiatrist (Kranenburg et al., 2008, Baskin, 2009, Potts, 2009, Petrini, 2010, Neuberger, 2011), surveys reporting the views of transplant physicians (Fortin et al., 2008) and articles discussing the role of UKDs in initiating living donor chains (Brook and Nicholson, 2006, Woodle et al., 2010, Melcher et al., 2013). The ethical, religious and practical aspects of UKD have also been discussed at length (Kaplan and Polise, 2000, Broyer and Affleck, 2000, Frunza et al., 2010, Hilhorst et al., 2011) with many arguments both for and against UKD. One study has demonstrated that significant numbers of individuals interested in UKD are psychologically stable (Henderson et al., 2003) and two studies have demonstrated comparative physical outcomes (Morrissey et al., 2005, Griffin and Morton, 2011) between UKDs and SKDs.
Articles reporting psychosocial outcomes after UKD can be divided into two groups: those reporting anecdotal feedback obtained as part of UKD follow up (Morrissey et al., 2005, Jacobs et al., 2004) (group one) and those where data was collected for research purposes, either qualitatively (Tong et al., 2012b, Clarke et al., 2013) or quantitatively (Jendrisak et al., 2006, Lennerling et al., 2008, Massey et al., 2010, Rodrigue et al., 2011, Timmerman et al., 2013) (group two).

Group one (anecdotal, donor reported outcomes) contains two studies with forty UKDs in total. The findings are encouraging with no reported adverse consequences after donation (Morrissey et al., 2005) and no reported negative outcomes in those with a previous mental health history (Jacobs et al., 2004). Donors were thankful for the opportunity to donate, were pleased that they had done so and did not exhibit any feelings of regret. Deviations from hospital protocol had taken place in two instances where donors had located their recipient immediately after the transplant had taken place (Jacobs et al., 2004). One donor had reported a dissatisfaction with the limited relationship between him and his recipient (Morrissey et al., 2005) and some UKDs had reported unexpected stress associated with increased tensions within personal relationships and with regard to financial matters (Jacobs et al., 2004).

Group two contains five observational questionnaire studies and two qualitative interview studies. Of the five questionnaire studies all have sample sizes of less than 50 UKDs and only one has used a comparison group of SKDs (Rodrigue et al., 2011). The details of these studies are summarised in Table 7.1. In conclusion, they demonstrate that a small number of UKDs have experienced psychological symptoms following donation, including low mood and anxiety (Lennerling et al., 2008, Massey et al., 2010, Rodrigue et al., 2011), some without a clear precipitating cause. Identifiable causes include both a breach of anonymity and lack of contact from the recipient. Both Dutch studies (Massey et al., 2010, Timmerman et al., 2013) (the latter of which is an update on the first and therefore includes some of the same patients) demonstrate an increase in overall psychological symptoms, anxiety, depressive symptoms, somatisation and hostility after donation, however all remain within the normal range of scores obtained from the general Dutch population. The same studies both highlighted an increase in sleep disturbance above the normal range; however on neither occasion was this found to be clinically significant. Natural fluctuations in psychological symptoms in SKDs have been also been demonstrated, although the results are, in part, contradictory (Clemens et al., 2006).
<table>
<thead>
<tr>
<th>Source</th>
<th>Primary Location</th>
<th>No. of donors</th>
<th>Design</th>
<th>Factors measured (method used)</th>
<th>Post-operative outcomes and conclusions</th>
</tr>
</thead>
</table>
| Jendrisak et al. (2006) AJT   | Washington, USA  | 6 UKD, 1 ULD | Retrospective| Post-donation satisfaction  
1. Survey performed at 6-8 weeks; 2. Interview performed by the program psychologist at 3 months | Donors reported a high degree of self-satisfaction and no psychological problems after donation. No donor regretted donating and all would be willing to donate again. |
| Lennerling et al. (2008) Clin Trans | Göteborg, Sweden | 3 UKD      | Retrospective| Psychological outcomes (donor reported)  
Psychosocial aspects of donation (self-designed questionnaire - 18 questions; Qu. Distributed 6m post-donation) | 2 donors reported no personal, psychological or emotional consequences post-donation. 1 donor felt ‘miserable and anxious’ immediately post-donation with no clear cause. Symptoms settled within 4 weeks. The donation questionnaire was completed by 2 donors, both of whom were satisfied following donation and neither of whom regretted donating. |
| Massey et al. (2010) AJT      | Rotterdam, The Netherlands | 20 UKD*      | Retrospective| Psychological functioning (1x validated questionnaire – SCL-90 (90 items))  
Mental health history and psychosocial aspects of donation (2x Semi-structured interviews) | Carefully screened UKDs appear to have no negative psychosocial consequences following donation. Self-rated impact of donation on psychological wellbeing and satisfaction were high. There was no reported regret. Negative impact on psychosocial wellbeing was related to a lack of recipient contact, feeling a need for greater contact with other living donors and post-operative complications. 1 donor reported increased anxiety post-donation. Recovered fully with additional psychosocial support. |
These samples of UKDs were subdivided into unspecified donations to a stranger (UKDs as defined in this chapter) and specified donations to a stranger, also known as ‘directed altruistic donations’. This is where a living donor donates to a named individual with whom they have become acquainted for the sole purposes of donation. There were 4 such donors in the paper by Massey et al and 20 such donors in the paper by Rodrigue et al.

† 24 of these UKDs are also included in the paper by Massey et al (2010).

<table>
<thead>
<tr>
<th>Source</th>
<th>Primary Location</th>
<th>No. of donors</th>
<th>Design</th>
<th>Factors measured (method used)</th>
<th>Post-operative outcomes and conclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rodrigue et al. (2011) Transplantation</td>
<td>Boston, USA</td>
<td>39 UKD* 50 SKD</td>
<td>Retrospective</td>
<td>Psychosocial aspects of donation (Self-design questions, donor reported and 1x validated questionnaire: Living Donor Expectancies Questionnaire – LDEQ; 42 items) Health related quality of life (HRQoL) (Short-form 36 (SF-36))</td>
<td>UKDs experience a similar psychosocial outcome to, and no greater adverse consequences than, SKDs. UKDs proceed to donation with a lesser sense of pressure or coercion. Regret was reported as 8% in UKDs (8 donors) and 2% in SKDs (1 donor). Psychosocial problems for both groups included depression (3 donors), anxiety (3 donors), trouble acquiring life / health insurance (8 donors) and financial issues (4 donors). 2 UKDs reported conflict with their family about their decision to donate. There was no significant difference between UKDs and SKDs in HRQoL as measured by the SF-36.</td>
</tr>
<tr>
<td>Timmerman et al. (2013) Transplantation</td>
<td>Rotterdam, The Netherlands</td>
<td>49 UKD†</td>
<td>Prospective</td>
<td>Psychological functioning (1x validated questionnaire – SCL-90 (90 items); given pre and post-donation) Psychosocial aspects of donation (self-designed questionnaire)</td>
<td>Some psychological symptoms increased post-donation (total score, depression, anxiety, somatisation, hostility and sleep problems), however all (except sleep problems) remained within the normal range for the Dutch population and were comparable to normal fluctuations in psychological symptoms. Only 2 donors’ increased scores were found to be clinically significant.</td>
</tr>
</tbody>
</table>
The study by Rodrigue and colleagues (Rodrigue et al., 2011) is the only one to compare UKDs with SKDs. As noted in Table 7.1, the UKD sample in this study is a mixture of those donating anonymously to a stranger and those who donate to a named individual with whom they have become acquainted for the sole purpose of donation (known as “directed altruistic donation”). Comparable psychosocial outcomes between UKDs and SKDs were found. This study reported the highest proportion of UKDs who regretted donating (3 UKDs; 8%) and the highest proportion of UKDs reporting symptoms of depression (3 UKDs; 8%) or anxiety (3 UKDs; 8%). Due to a mixed sample of UKDs being grouped together in the analysis it is not possible to tell whether the type of donation (true unspecified donation or directed altruistic donation) was implicated. It is also unclear whether depression and anxiety co-existed with one another or whether these psychological symptoms were associated with regret. It should be noted that symptoms of depression and anxiety were donor reported rather than measured objectively.

Social issues were not identified in every study, however when reported included financial difficulties and familial conflicts. Financial issues were noted in the American studies (Jendrisak et al., 2006, Rodrigue et al., 2011) as an unanticipated source of stress. These occurred when there were difficulties in obtaining life or health insurance and when recovery took longer than expected and more time was taken away from work (Jacobs et al., 2004). Familial conflicts were common (up to 30% in some cases) and were associated with the donors’ decision to donate, where their loved ones were concerned for their health and wellbeing and when the desire to donate was poorly understood (Massey et al., 2010, Rodrigue et al., 2011). A lack of social support was identified by Massey et al as being a source of increased psychological symptoms after donation.

The two qualitative studies exploring UKD included samples of 18 (Clarke et al., 2013) and 14 (Tong et al., 2012b) post-operative donors respectively, who were interviewed on a single occasion using in-depth and semi-structured interviews. Both sets of data were analysed using a grounded theory approach. These studies have further established an absence of regret and a lack of psychosocial issues after donation. Donors reported the experience of donating as being very positive and empowering with continuous and far reaching outcomes for both themselves and their recipient. Some reported an increase in self-esteem and that donation had become a positive emotional anchor that they referred to in times of difficulty (Tong et al., 2012b). UKDs
had found the psychiatric assessment conducted as part of their workup difficult as they were made to feel as though they had to prove their sanity. Clarke et al also highlighted UKDs’ awareness of negative attitudes within transplant teams, which had manifested as inconsistent and confusing information provided by different members of the team. The same study also identified that UKDs found it difficult to embrace the patient role (as they had adopted it through choice) and that a lack of communication in the form of a card from the recipient was disappointing to the donor, as this was seen as an incongruent response to their donation gift.

UKDs’ motivations were investigated in both qualitative studies and two of the questionnaire studies (Massey et al., 2010, Rodrigue et al., 2011). Donors commonly cited more than one reason for wanting to donate and were motivated by a strong desire to help someone who was in need. UKDs consistently demonstrated other forms of altruistic behaviour (i.e. blood or bone marrow donation and charitable donations) and they perceived their desire to help others as being consistent with their moral beliefs and values. It was not uncommon for UKDs to know someone who had received a transplant or someone who had been a living donor. These findings should be interpreted with caution as they would have been elicited from UKDs who had been allowed to donate. It is possible that those who had motivations which were not perceived as being genuine would not have passed the pre-operative assessment process.

Despite the largely positive findings from these studies, the transplant community continues to approach UKDs with a degree of caution, cynicism and suspicion. This suggests that transplant professionals may not be aware of the data available or, more likely, that it does not provide sufficiently convincing evidence to change opinions. All of the studies discussed above are limited by small sample sizes, two of which contain less than ten UKDs. The study by Rodrigue et al is strengthened by the use of a comparison group, however the UKD sample is mixed and it is unclear whether the reported negative psychosocial outcomes in some donors are related to the type of UKD that has taken place. The papers by Massey et al and Timmerman et al have a crossover patient sample and, in addition, the SCL-90 questionnaire administered was done so as part of the UKDs’ clinical workup. It is a possibility that the donors would have answered favourably, underplaying their psychological symptoms, in order to increase their chances of being allowed to donate; a finding previously demonstrated in other living donor cohorts (Hurst et al., 2010). Both qualitative studies contain good
sample sizes and a robust methodology, however the primary focus of these studies was to elicit the motivations and experiences of UKD rather than conclusively comment on psychosocial outcomes.

The principal concerns of the transplant community can be summarised into two key questions. Firstly, what characteristics and motivations result in someone becoming a UKD? Secondly, is the practice safe in terms of psychosocial and physical outcomes and do donors experience regret after donating? In an attempt to answer these questions a retrospective cross-sectional case-control study was performed. As the UK scheme is centrally co-ordinated and requires mandatory registration and follow up of all living donors, this provided a unique opportunity to perform a nationwide study of all UKDs who had donated in the United Kingdom since the practice became legal in 2006. Although a longitudinal study comparing pre- and post-operative outcomes would have been more informative, the small numbers of UKDs per year would mean that a study with a sample size of more than fifty donors would have taken several years to complete. The nationwide UKD sample was compared with a local sample of SKDs. The rationale for including a comparison group was to provide a standard against which the UKD sample could be compared. It was deemed necessary to do this in order to help the transplant community interpret the results within the context of SKD, which is deemed an acceptable practice.

**Study aims**

The aims of this study were devised following a review of the literature and a meeting between members of the research team. A detailed assessment of psychosocial outcomes was deemed necessary due to the many unanswered questions that persisted following the literature review. A separate assessment of UKDs’ motivations and the level of post-operative contact were also necessary as quantitative data on the British UKD population was unavailable. The degree of contact between UKDs and their recipients was assessed in particular detail as this was found to be a main cause for concern within the transplant community.

This study had four principal aims:

1. To assess the motivations of UKDs
2. To assess psychosocial and physical outcomes in UKDs and compare these to SKDs
3. To determine the prevalence of donors who regret donation and whether this is related to outcome
4. To establish the extent of contact between UKDs and their recipients, and whether this is related to outcome

**Methods**

**Sample**

A cross-sectional evaluation of donor motivations, experiences and psychosocial outcomes was conducted in a national, consecutive sample of UKDs. The sample included all 148 UKDs who had donated in the UK since the scheme began in 2006 until November 2012. UKDs were recruited using a database obtained from NHSBT. The UKD sample was compared with 148 SKDs recruited from Guy's Hospital. Every SKD undergoing surgery at Guy's Hospital between 2007 and July 2012 was considered for inclusion. Those SKDs who had not been followed up at Guy's Hospital and those involved in other psychology research studies (40 patients involved in a prospective quantitative study running simultaneously – chapter 5) were excluded. A list of 298 donors remained which was then sorted by date of donation. Alternate names were then selected.

All donors were sent a questionnaire by post and were provided with an option to complete it on paper or online via a secure, encrypted and password protected website. One postal reminder was sent after four weeks. The questionnaire consisted of three sections:

**Section 1:** Included twelve validated questionnaires investigating a range of psychosocial factors (Table 7.2). The factors measured and the validated questionnaires used were the same as used in the longitudinal study outlined in chapters 4 and 5 of this thesis. As before, validated abbreviated versions of questionnaires were utilised where possible to decrease responder burden.

**Section 2:** Included demographic questions: ethnicity, religious beliefs, highest level of education, current employment and relationship status, number of children, and number of dependents in the household. The UKD sample was additionally asked when and where they had donated and how they had become aware of the possibility of being an unspecified donor.
Table 7.2 - Validated questionnaires

<table>
<thead>
<tr>
<th>Psychosocial factor</th>
<th>Validated measure selected</th>
<th>Min-Max scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wellbeing</td>
<td>Office of National Statistics Wellbeing questions</td>
<td>0-40</td>
</tr>
<tr>
<td>Distress</td>
<td>General Health Questionnaire 12 (GHQ-12)</td>
<td>0-36</td>
</tr>
<tr>
<td>Depression</td>
<td>Patient Health Questionnaire 2 (PHQ-2)</td>
<td>0-6</td>
</tr>
<tr>
<td>Stress</td>
<td>4 item Perceived Stress Scale (PSS)</td>
<td>0-20</td>
</tr>
<tr>
<td>Health-related Quality of Life</td>
<td>Short Form 12 (Physical components only)</td>
<td>7-31</td>
</tr>
<tr>
<td>Life Satisfaction</td>
<td>Satisfaction with life scale (SWLS)</td>
<td>5-35</td>
</tr>
<tr>
<td>Self-Esteem</td>
<td>Rosenberg</td>
<td>0-30</td>
</tr>
<tr>
<td>Personality</td>
<td>10 item personality inventory (TIPI)</td>
<td>0-20†</td>
</tr>
<tr>
<td>Anxiety</td>
<td>6-item State-Trait Anxiety Inventory (STAI-short)</td>
<td>6-24</td>
</tr>
<tr>
<td>Social support</td>
<td>Multidimensional Scale of Perceived Social Support</td>
<td>12-84</td>
</tr>
<tr>
<td>Optimism</td>
<td>Life Orientation Test - Revised</td>
<td>0-24</td>
</tr>
<tr>
<td>Social comparison</td>
<td>Social Comparison Scale</td>
<td>11-110</td>
</tr>
</tbody>
</table>

†per trait

Section 3: Included questions related to pre-operative medical history (including surgical procedures and mental health) and post-operative recovery (complications, residual pain and return to driving, work and normal function). Both groups were also asked ten questions about their feelings towards their donation (Appendix 5) and were provided with a 5-point Likert scale (strongly disagree to strongly agree). These were the same questions given in the longitudinal study at three and twelve months and had therefore similarly been tested for face and content validity on a sample of 20 SKDs and modified accordingly before being retested and finalised. Further validation tests were not performed on any UKDs in order to guarantee that all UKDs would be eligible for inclusion in the main study.

Both groups were also asked questions related to alternative markers of altruism. They were asked to answer yes, no or not any more to whether they were a blood donor, whether they were on the bone marrow or organ donor register, whether they made regular charitable donations and whether they regularly performed volunteer
work. The UKD sample received additional questions about motivation (Appendix 6), the degree of contact they had had with their recipient and their intentions for future contact. These questions were based on those used in other UKD studies and had also been tested for face and content validity as above.

Both questionnaires concluded with a free text space to allow for elaboration of previously answered questions or to document additional information. These were analysed using framework analysis; a method of thematic analysis developed and described by Ritchie and Spencer (Ritchie and Spencer, 1994). This method was selected because it had become familiar through its use in the qualitative study (chapter 3) and because it permitted a systematic, methodical and comprehensive approach to the data. This analysis was conducted without the use of computer software and was performed by a single researcher (NHM). Further details about the stages of framework analysis are outlined in chapter 3.

A retrospective evaluation of clinical outcomes at 12 and 24 months was also performed. Physical outcome data for all living donors is held on a central database by NHSBT and data for the UKD sample (including non-responders) was cross-linked securely from this database using the national organ donor number. Post-operative physical outcome data included clinical measures, such as blood pressure readings, length of stay, complications and blood test results (Estimated Glomerular Filtration Rate [eGFR], serum creatinine, and haemoglobin). Physical outcome data for the SKD group was obtained locally from hospital records. An analysis of responders vs. non-responders was performed focusing on length of stay, major complications, and the year of donation to determine whether those who had not responded had experienced inferior physical outcomes. Both groups were additionally asked to self-report their length of stay, the presence of complications and the length of time they required to recuperate.

**Ethical approval**

NHS research ethics approval was obtained (09-H0804-31). A formal consent form was not required as consent was presumed with the return of a completed questionnaire.
Statistical Analysis

Parametric and non-parametric tests were performed as appropriate following normality testing. Comparisons between UKD and SKD groups were evaluated using Chi-Square (Fisher's Exact test), t-test, and ANOVA models as appropriate. Unadjusted and adjusted mean differences between the donor groups for the psychological variables were calculated using multivariable linear regression analysis. To control for potential confounding effects, adjustment controlled for age at donation, time since donation, sex, number of children, ethnicity (White vs Non-White), and education (Higher education vs Less than higher education). Both unadjusted and adjusted mean difference scores (standard errors) are presented. P values <0.05 were considered as significant. Presence of missing data for the variables in the analysis was low, ranging between 0 and 12 observations per variable (0 and 6.3%). Since the spread of missing data across variables meant omitting between 10 (5.3%) and 21 (11.1%) observations in the complete case analysis to calculate adjusted mean group differences, a multiple imputation analysis was conducted where missing data were imputed across 10 data sets using the chained equations approach (van Buuren et al., 1999). The results from the multiple imputation analysis are provided in Table 7.9 (Appendix 7). As the proportion of missing data for individual variables was low, sensitivity analysis for a non-ignorable missingness was not necessary. Statistical analysis was performed using SPSS (version 22) and Stata (version 12.1).

Results: Demographics, motivations, attitudes and quantitative psychosocial outcomes

Demographics

190 responses were received from the 296 questionnaires distributed (64.2% total response rate). There was a significant difference between the groups in the number of responses received (110 UKD (74.3%) vs. 80 SKD (54.1%) (p<0.001)). Table 7.3 displays the demographic data for both groups. The UKD group were on average 10 years older and predominantly of white ethnicity. UKDs were less likely to be currently working (33.9% retired), have children, or have current dependents. There was no difference in medical history between the two groups, but the UKD group were found to have a significantly higher incidence of previous surgery (66 UKDs vs. 31 SKDs; p=0.004). This may be accounted for by the increased age of the UKD group. Despite no difference in mental health history the UKD group had more commonly experienced episodes of low mood lasting more than 2 weeks. Geographical data was limited but
<table>
<thead>
<tr>
<th>Table 7.3 - Demographic details</th>
<th>Unspecified Kidney Donors (UKD) (%)</th>
<th>Specified Kidney Donors (SKD) (%)</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>59 (53.6)</td>
<td>38 (47.5)</td>
<td>0.403</td>
</tr>
<tr>
<td>Female</td>
<td>51 (46.4)</td>
<td>42 (52.5)</td>
<td></td>
</tr>
<tr>
<td>Mean age at donation</td>
<td></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Range</td>
<td>54 (SD 13.58)</td>
<td>44 (SD 10.79)</td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>108 (99.1)</td>
<td>62 (78.5)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Non-white</td>
<td>1 (0.9)</td>
<td>17 (21.5)</td>
<td></td>
</tr>
<tr>
<td>Religious beliefs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>60 (54.5)</td>
<td>52 (65.8)</td>
<td>0.12</td>
</tr>
<tr>
<td>None</td>
<td>50 (45.5)</td>
<td>27 (34.2)</td>
<td></td>
</tr>
<tr>
<td>Highest level of education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Higher education</td>
<td>64 (58.7)</td>
<td>39 (51.3)</td>
<td>0.319</td>
</tr>
<tr>
<td>Other / no education</td>
<td>45 (41.3)</td>
<td>37 (48.7)</td>
<td></td>
</tr>
<tr>
<td>Employment status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Currently working</td>
<td>68 (62.4)</td>
<td>67 (83.8)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Retired</td>
<td>37 (33.9)</td>
<td>8 (10)</td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>4 (3.7)</td>
<td>5 (6.2)</td>
<td></td>
</tr>
<tr>
<td>Relationship status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married / Long-Term partner /</td>
<td>69 (62.7)</td>
<td>63 (79.7)</td>
<td>0.012</td>
</tr>
<tr>
<td>Widowed</td>
<td>41 (37.3)</td>
<td>16 (20.3)</td>
<td></td>
</tr>
<tr>
<td>Children</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>65 (59.1)</td>
<td>59 (73.8)</td>
<td>0.036</td>
</tr>
<tr>
<td>No</td>
<td>45 (40.9)</td>
<td>21 (26.2)</td>
<td></td>
</tr>
<tr>
<td>Current Dependents</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 18</td>
<td>7 (6.4)</td>
<td>13 (16.2)</td>
<td>0.028</td>
</tr>
<tr>
<td>&gt; 18</td>
<td>6 (5.5)</td>
<td>12 (15)</td>
<td>0.027</td>
</tr>
<tr>
<td>Previous medical history</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>27 (24.5)</td>
<td>13 (16.2)</td>
<td>0.166</td>
</tr>
<tr>
<td>No</td>
<td>83 (75.5)</td>
<td>67 (83.8)</td>
<td></td>
</tr>
<tr>
<td>Previous surgical history</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>66 (60)</td>
<td>31 (38.8)</td>
<td>0.004</td>
</tr>
<tr>
<td>No</td>
<td>44 (40)</td>
<td>49 (61.3)</td>
<td></td>
</tr>
<tr>
<td>Previous mental health history</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>31 (28.2)</td>
<td>15 (18.8)</td>
<td>0.134</td>
</tr>
<tr>
<td>No</td>
<td>79 (71.8)</td>
<td>65 (81.2)</td>
<td></td>
</tr>
<tr>
<td>Formal mental health diagnosis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>received</td>
<td>8 (25.8)</td>
<td>4 (26.7)</td>
<td>0.950</td>
</tr>
<tr>
<td>Yes</td>
<td>23 (74.2)</td>
<td>11 (73.3)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental health treatment received</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>27 (87.1)</td>
<td>14 (93.3)</td>
<td>0.524</td>
</tr>
<tr>
<td>No</td>
<td>4 (12.9)</td>
<td>1 (6.7)</td>
<td></td>
</tr>
<tr>
<td>Episodes of low mood lasting &gt; 2w</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>63 (57.3)</td>
<td>32 (40)</td>
<td>0.019</td>
</tr>
<tr>
<td>No</td>
<td>47 (42.7)</td>
<td>48 (60)</td>
<td></td>
</tr>
</tbody>
</table>
demonstrated that only a small number of UKDs donated away from their nearest transplant centre (7 vs. 80 donors; \( p<0.001 \)).

**Motivations and donor characteristics**

The majority of UKDs were made aware of unspecified donation through the media (64 donors (58.2%) – Radio 23 (20.9%), Television 16 (14.5%), Newspaper 14 (12.7%), Internet 6 (5.5%), Magazines 5 (4.5%)) or through researching other forms of donation (10 donors (9.1%)). Other modes included knowing someone with renal failure (7.3%), knowing someone with a transplant (5.5%), and knowing someone who had been a living kidney donor (UKDs or SKDs) (5.5%). A minority were made aware by family, friends or a religious organisation (3.6%), had heard about UKD through their job (5.5%) or considered the idea of their own accord (2.7%). The most common reasons for donating were "I thought my donation would make little difference to my own life but a huge difference to someone else's" (30 UKDs (27.3%)) and "I wanted to help someone" (13 UKDs (11.8%)).

There was no significant difference in personality traits between the two groups across each of the five personality domains measured by the Ten Item Personality Inventory (TIPI) (extraversion \( p=0.586 \), agreeableness \( p=0.719 \), conscientiousness \( p=0.719 \), emotional stability \( p=0.418 \) and openness \( p=0.948 \)). The UKD group were found to be more altruistic when compared with the SKD group across five separate markers of altruism: Blood donation (77.3% vs. 45.0%; \( p<0.001 \)), bone marrow registration (30.3% vs. 7.5%; \( p=0.001 \)), organ donor registration (94.5% vs. 58.8%; \( p<0.001 \)), participation in volunteer work (56.4% vs. 32.5%; \( p=0.001 \)), and monetary donations to charity (82.7% vs. 65.0%; \( p=0.005 \)).

**Post-operative psychosocial outcomes**

The UKD group donated more recently (1.3 years vs. 2.6 years; \( p<0.001 \)) which reflects the increase in numbers of people becoming UKDs in the past 12 months. Table 7.4 contains both unadjusted and adjusted difference scores for each of the psychosocial measures used. Adjusted models controlled for age at donation, time since donation, sex, children, ethnicity, and education. In both the unadjusted and adjusted models there was no significant difference demonstrated in post-operative psychological symptoms, such as depression, distress, stress or anxiety (\( p>0.05 \)). UKDs and SKDs additionally demonstrated equivalent wellbeing, life satisfaction, optimism and self-
<table>
<thead>
<tr>
<th>Measured Outcome</th>
<th>Specified Kidney Donors</th>
<th>Specified Kidney Donors</th>
<th>Unadjusted mean difference</th>
<th>Adjusted mean difference*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>Mean</td>
<td>SD</td>
<td>n</td>
</tr>
<tr>
<td>Wellbeing</td>
<td>109</td>
<td>30.28</td>
<td>6.90</td>
<td>78</td>
</tr>
<tr>
<td>Life Satisfaction</td>
<td>110</td>
<td>24.67</td>
<td>7.42</td>
<td>77</td>
</tr>
<tr>
<td>Stress</td>
<td>109</td>
<td>4.03</td>
<td>3.18</td>
<td>80</td>
</tr>
<tr>
<td>Distress</td>
<td>109</td>
<td>9.99</td>
<td>4.74</td>
<td>78</td>
</tr>
<tr>
<td>Depression</td>
<td>106</td>
<td>0.66</td>
<td>1.41</td>
<td>80</td>
</tr>
<tr>
<td>Anxiety</td>
<td>107</td>
<td>10.02</td>
<td>3.86</td>
<td>77</td>
</tr>
<tr>
<td>Physical Health-Related Quality of Life</td>
<td>107</td>
<td>27.86</td>
<td>4.56</td>
<td>78</td>
</tr>
<tr>
<td>Self-Esteem</td>
<td>107</td>
<td>22.11</td>
<td>5.18</td>
<td>76</td>
</tr>
<tr>
<td>Optimism</td>
<td>108</td>
<td>21.68</td>
<td>6.79</td>
<td>79</td>
</tr>
<tr>
<td>Social support</td>
<td>105</td>
<td>62.05</td>
<td>16.85</td>
<td>77</td>
</tr>
<tr>
<td>Social comparison</td>
<td>100</td>
<td>65.98</td>
<td>13.97</td>
<td>78</td>
</tr>
</tbody>
</table>

* adjusted for age at donation, sex, children, ethnicity, education, time since donation
esteem across both unadjusted and adjusted models (p>0.05). Furthermore, scores from the physical component of the SF12 were equivalent (UKD 27.86 vs. SKD 28.01; p>0.05), despite the increased age in the UKD group. In the unadjusted model a significant difference was demonstrated in the perceived level of social support (UKD 62.05 vs. SKD 67.60; p=0.02) and social comparison (i.e. where one sees oneself in relation to others) (UKD 65.98 vs. SKD 71.38; p=0.011), but this difference became insignificant in the adjusted model (p=0.151 and p=0.056, respectively).

**Physical outcomes**

Limited 12 and 24 month clinical follow up data were available due to many UKDs donating fewer than 2 years before the study commenced (70 UKDs, 63.6%). Objective physical outcome measures were not found to be statistically different between the groups at 12 or 24 month follow up time points when adjusted for age, gender and pre-operative values (Table 7.5).

<table>
<thead>
<tr>
<th>Physical Outcome Variable</th>
<th>Unspecified Kidney Donors (UKD)</th>
<th>Specified Kidney Donors (SKD)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>Mean</td>
</tr>
<tr>
<td><strong>12 months</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Systolic Blood Pressure</td>
<td>48</td>
<td>126.2</td>
</tr>
<tr>
<td>Diastolic Blood Pressure</td>
<td>48</td>
<td>76.9</td>
</tr>
<tr>
<td>eGFR</td>
<td>53</td>
<td>59.0</td>
</tr>
<tr>
<td>Serum creatinine</td>
<td>53</td>
<td>109.3</td>
</tr>
<tr>
<td>Haemoglobin</td>
<td>50</td>
<td>13.7</td>
</tr>
<tr>
<td><strong>24 months</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Systolic Blood Pressure</td>
<td>25</td>
<td>125.5</td>
</tr>
<tr>
<td>Diastolic Blood Pressure</td>
<td>25</td>
<td>79.0</td>
</tr>
<tr>
<td>eGFR</td>
<td>29</td>
<td>59.5</td>
</tr>
<tr>
<td>Serum creatinine</td>
<td>29</td>
<td>106.7</td>
</tr>
<tr>
<td>Haemoglobin</td>
<td>23</td>
<td>13.7</td>
</tr>
</tbody>
</table>

*Adjusted for age, gender and pre-operative values*
There was no significant difference between the two groups in the rate of patient reported complications, the number of complications requiring further admissions to hospital or the number of complications requiring further surgery (Table 7.6). A surgical complication is considered to be any deviation from the ideal postoperative course that is not inherent in the procedure and does not comprise a failure to cure (Dindo and Clavien, 2008). A list of common post-operative complications was provided for donors to select from.

**Table 7.6 – All complications**

<table>
<thead>
<tr>
<th></th>
<th>UKD</th>
<th>SKD</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did you have any complications after your surgery?</td>
<td>Yes (33.6%)</td>
<td>Yes (35.0%)</td>
<td>0.845</td>
</tr>
<tr>
<td>Did any of these complications require further admissions to hospital?</td>
<td>11 (10%)</td>
<td>8 (10%)</td>
<td>0.956</td>
</tr>
<tr>
<td>Did any of these complications require further surgery?</td>
<td>3 (2.7%)</td>
<td>6 (7.5%)</td>
<td>0.121</td>
</tr>
</tbody>
</table>

Additional free space was made available for further elaboration or to document complications that were not listed. The results were combined with data obtained from NHSBT and are displayed in Table 7.7. They are divided into peri-operative complications arising within the first thirty days after surgery and those occurring thereafter. Rates of conversion from a laparoscopic procedure to an open procedure were very small (UKD 2 vs. SKD 1) and were all for intra-operative bleeding. The major complications experienced by the UKD group (regarded as any potentially life-threatening complication with the need for intervention) (Dindo et al., 2004) included post-operative pneumonia requiring additional days in hospital (2 patients), intra-operative haemorrhage requiring blood transfusion (1 patient), pulmonary embolus (1 patient) and cerebrovascular accident (stroke) occurring whilst under general anaesthetic (1 patient). There was no significant difference in age or gender in those experiencing a major complication (Major complication mean age 52.8 years vs. no major complication mean age 49.8; p=0.626).
Presence of complications, readmission to hospital and the need for further operations did not correlate with any of the psychosocial factors measured in the UKD group, as measured by an independent samples t-test. In the SKD group the presence of complications was associated with inferior wellbeing (ONS score: 32.26 vs. 28.36; \( p=0.015 \)). There was no significant difference in length of stay between the 2 groups (UKD 3.65 days vs. SKD 3.95 days; \( p>0.05 \)). Post-operative outcome data for all UKDs was made available from NHS Blood and Transplant. There was no difference in post-operative outcomes (blood results, blood pressure, rate of complications, length of stay) between responders and non-responders.
Subjective markers of recovery

Subjective, patient reported markers of recovery demonstrated faster recovery in the UKD group. Donors were asked to select a time frame in which they returned to work and driving (Less than 4 weeks, 4-6 weeks, 6-12 weeks or more than 12 weeks). UKDs returned to work faster (25 UKDs 4-6 weeks vs. 30 SKDs 6-12 weeks; *p*<0.001) and returned to driving faster (52 UKDs <4 weeks vs. 23 SKDs 6-12 weeks; *p*<0.001). Donors were additionally asked to note how many weeks it took for them to feel back to normal. The median return to normal time for UKDs was 6 weeks versus 12 weeks for the SKD group (*p*=0.001). There was no significant difference in residual operative site pain (*p*=0.156).

Attitudes towards donation

Answers to the attitudes towards donation questions (Appendix 5) were given on a Likert scale (strongly agree to strongly disagree). All questions, except the question on regret, were dichotomised for the purposes of analysis. Those who answered a statement with "strongly agree" or "agree" were categorised as agreeing with the statement. Those who answered a statement with "strongly disagree" or "disagree" were categorised as disagreeing with the statement. A "neither agree nor disagree" answer was regarded to be a display of ambivalence towards that statement and therefore these answers were categorised as the participant disagreeing with the statement. These answers are displayed in Table 7.8.

These questions demonstrate that both groups thought that organ donation in general was a good thing, both groups felt good about being living kidney donors and both groups were likely to continue feeling similarly regardless of what happened in the future (low anticipated regret). Both groups felt that donation was one of the best things they had done, yet less than half in each group felt that donating had increased their self-esteem. Some significant differences were demonstrated between the two groups. The UKDs had received less support for their donation (Table 7.8, question 3) and had been praised less for donating (Table 7.8, question 6). The SKD sample considered their donation as a more significant life event (*p*=0.002). Current regret was low for both groups (4 UKDs (3.7%) vs. 6 SKDs (7.5%); *p*=0.078) with two SKDs feeling ambivalent about donation (2.5%).
Table 7.8 - Attitudes towards donation

<table>
<thead>
<tr>
<th></th>
<th>UKD Agree</th>
<th>UKD Disagree</th>
<th>SKD Agree</th>
<th>SKD Disagree</th>
<th>P value (Chi²)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I think organ donation (in general) is a good thing</td>
<td>109</td>
<td>1</td>
<td>80</td>
<td>0</td>
<td>0.240</td>
</tr>
<tr>
<td></td>
<td>99.1%</td>
<td>0.9%</td>
<td>100%</td>
<td>0%</td>
<td></td>
</tr>
<tr>
<td>I feel good about being a Living Kidney Donor</td>
<td>106</td>
<td>4</td>
<td>76</td>
<td>4</td>
<td>0.504</td>
</tr>
<tr>
<td></td>
<td>96.4%</td>
<td>3.6%</td>
<td>95%</td>
<td>5%</td>
<td></td>
</tr>
<tr>
<td>The people closest to me supported my decision to be a Living Kidney Donor</td>
<td>73</td>
<td>37</td>
<td>74</td>
<td>6</td>
<td>&lt;0.001*</td>
</tr>
<tr>
<td></td>
<td>66.4%</td>
<td>33.6%</td>
<td>92.5%</td>
<td>7.5%</td>
<td></td>
</tr>
<tr>
<td>Donating a kidney is one of the best things I have ever done</td>
<td>99</td>
<td>11</td>
<td>78</td>
<td>2</td>
<td>0.172</td>
</tr>
<tr>
<td></td>
<td>90%</td>
<td>10%</td>
<td>97.5%</td>
<td>2.5%</td>
<td></td>
</tr>
<tr>
<td>If I had my time again I would not choose to be a Living Kidney Donor</td>
<td>4</td>
<td>105</td>
<td>6</td>
<td>74</td>
<td>0.078</td>
</tr>
<tr>
<td></td>
<td>(3.7%)</td>
<td>(96.3%)</td>
<td>(7.5%)</td>
<td>(92.5%)</td>
<td></td>
</tr>
<tr>
<td>I have been praised for being a Living Kidney Donor†</td>
<td>91</td>
<td>16</td>
<td>75</td>
<td>5</td>
<td>0.011*</td>
</tr>
<tr>
<td></td>
<td>85.0%</td>
<td>15%</td>
<td>93.8%</td>
<td>6.2%</td>
<td></td>
</tr>
<tr>
<td>Being praised for being a Living Kidney Donor is not important to me†</td>
<td>74</td>
<td>35</td>
<td>49</td>
<td>31</td>
<td>0.344</td>
</tr>
<tr>
<td></td>
<td>67.8%</td>
<td>32.2%</td>
<td>61.3%</td>
<td>38.7%</td>
<td></td>
</tr>
<tr>
<td>Being a Living Kidney Donor has improved my self-esteem (how I see myself)</td>
<td>47</td>
<td>63</td>
<td>34</td>
<td>46</td>
<td>0.996</td>
</tr>
<tr>
<td></td>
<td>42.7%</td>
<td>57.3%</td>
<td>42.5%</td>
<td>57.5%</td>
<td></td>
</tr>
<tr>
<td>Being a Living Kidney Donor has changed my outlook on life†</td>
<td>31</td>
<td>77</td>
<td>38</td>
<td>42</td>
<td>0.035*</td>
</tr>
<tr>
<td></td>
<td>28.7%</td>
<td>71.3%</td>
<td>47.5%</td>
<td>52.5%</td>
<td></td>
</tr>
<tr>
<td>I will continue to feel the same way about being a Living Kidney Donor regardless of what happens in the future</td>
<td>104</td>
<td>6</td>
<td>70</td>
<td>10</td>
<td>0.220</td>
</tr>
<tr>
<td></td>
<td>94.5%</td>
<td>5.5%</td>
<td>87.5%</td>
<td>12.5%</td>
<td></td>
</tr>
</tbody>
</table>

† p<0.05
†† Missing data for UKD sample

Contact and Communication

The current UK living donor guidelines (British Transplantation Society, 2011) state that anonymity between the donor and recipient prior to surgery is required, as in keeping with the Human Tissue Authority’s code of practice (Human Tissue Authority, 2013). After the transplant has been performed, anonymity can be broken with the consent of both parties and typically this is facilitated through the living donor coordinators. In practice both UKDs and their recipients may be provided with non-identifiable information regarding the other party both before and after the transplant takes place. Exchanges of letters and cards are permitted soon after donation, however
further contact is recommended once a minimum of six months has passed to allow sufficient time for recovery.

Fifty-four (49.5%) UKDs received a card or a letter after their donation, the majority within 3 months of donating (70.1%). Of those who did not receive a card, the majority “would have liked” or “maybe would have liked” to receive one (87.3%). 71 UKDs (65.1%) had found out what had happened to the recipient following their donation and 2 donors experienced some regret at this knowledge (4.9%). Further contact (e.g. by telephone, email or letter) was minimal (14 donors; 12.8%) with only two pairs meeting in person (1.8%). Neither donor regretted meeting their recipient.

Results: Framework analysis of free text answers
A thematic analysis was performed on the free text answers provided at the end of the questionnaire. Significantly more free text contributions were made by the unspecified donor group (80 UKDs vs. 43 SKDs; \( p=0.007 \)). Five key themes were identified:

1. Motivation to donate
2. The Donation Experience
3. Attitudes of others
4. The recipient
5. Reflection on the donation experience

Each theme is discussed in detail below and verbatim quotes are provided. Responses from UKDs are represented by "UKD" and responses from SKDs are represented by "SKD", followed by the participant’s study number (allocated at random).

Theme 1: Motivation to donate
UKDs were motivated by a genuine desire to help others, which was consistent with their lifestyle, upbringing and morals. Donors perceived their own good health as a fortune that not everyone benefited from. Donating a kidney was a way of sharing this good fortune with someone less fortunate. Donation was not viewed as a major thing to do or an inconvenience:

“I told people... (including the psychiatrist) that I saw kidney donation as an extension of blood donating... It’s a bit of me I can do without that might do good to someone else... EVERYONE has said it was so much more serious, but I disagree” (UKD 140)
"My mother always carried a donor card. My father donated blood all his life and gave away his last penny. We were brought up to share or give away half of what we had" (UKD 094)

"All I had to do was to sign the consent form" (UKD 045)

"Donation interfered with my life very little" (UKD 030)

The desire to donate was also strong enough to overcome emotional obstacles, such as a fear of pain:

"I'm a complete coward about long term pain" (UKD 140)

Previous life experiences also contributed, such as knowing transplant recipients (renal, bone marrow), working with patients with renal failure and being an only child. Some felt that their donation was a way of paying the NHS back for care they or their loved ones had received:

"As an only child I had feelings for those on a list and having no one come forward for them" (UKD 133)

"I'm an ex renal nurse and saw first-hand the suffering that renal patients experience" (UKD 105)

"... I felt indebtedness to him, his team, and the NHS... [it] was a significant factor in my motivation" (UKD 013)

UKDs were surprised that so few people had been unspecified donors. They wished to increase the awareness of UKD and support others:

"...the important issue is to raise awareness of altruistic donation and the plight of those suffering from kidney failure" (UKD 055)

"I was a little shocked to find out how few altruistic donors there have been. I only wish that more people would undertake this procedure to help others" (UKD 045)

"I feel very motivated to encourage others to donate" (UKD 040)

In a more exceptional case, one donor referred to a period in his life where he had become depressed and had contemplated suicide. His decision to become an unspecified donor was prompted by the discovery that there was no guarantee that his organs would be suitable should he decide to take his own life; something which had been a key to justifying his decision to commit suicide:
“I felt profound fear at what my Maker would say to me if I deliberately ended my life... To waste those organs would be a terrible sin. I had to do what I could to ensure someone would benefit... I felt I could only face my Maker if I did all I could to ensure some good would come from my demise. I mistakenly thought that I could blow my brains out and medics would have a few hours to get what they wanted... I decided on my own that it would be best if I donated while alive. That way at least if something went wrong someone could benefit...” (UKD 102)

SKDs spoke much less of what motivated them to donate. For some, as noted in the qualitative study (chapter 3), the prospect of donation had been spoken of many years prior to it taking place and was viewed as a necessity to improve not only their recipient’s life but their own also:

“I had the idea of donating a kidney to my daughter for over ten years” (SKD 118)

“I did not want to donate a kidney to my husband but did so so that it would improve our lives together” (SKD 033)

Theme 2: The Donation Experience

Pre-operative

Donors within both groups had a positive view of their pre-operative workup, where the assessment process was seen as thorough and reassuring:

“The pre-operative assessment was thorough and concerned for my welfare” (UKD 041)

“I found all the pre-operation seminars of great benefit, it gave me the confidence to go ahead with my donation and it was helpful to have contact with other donors / recipients in the early weeks after the operation to compare how we were doing” (SKD 127)

“The pre-op care I received whilst the initial discussions and testing were going on was excellent” (SKD 130)

The UKD group experienced more delays within their workup period and subsequently reported that the process was too lengthy. Delays were frequently unexplained and donors felt they were left chasing the hospital for information. Those who were committed to donation felt that their lives had been put on hold whilst waiting to be told whether they would be suitable to donate:

“I was becoming frustrated [as it] took 12 months to the day to donate” (UKD 133)
“...application to donation took 20 months... once the mind is made up one wishes to get on with it. Some of the delays were unnecessary, 6 months at one stage for no apparent reason” (UKD 147)

“The whole experience has been a test of endurance. This is not because of the tests but the lack of communication. I have constantly had to ring to find out what was happening [and]... I have felt like a bit of a nuisance” (UKD 138)

“The worst experience of all was the "battle" to be allowed to donate” (UKD 016)

“I think the process should be made as efficient as possible over a reasonable time, not a long drawn out marathon with multitudes of hurdles to climb just to prove you know what you are doing and have the determination to finish the course” (UKD 060)

The delays encountered as part of the process were challenging for some and led to a loss of faith and confidence in the UK system:

“It nearly caused me not to donate. I seriously thought about donating abroad...”
(UKD 090)

Donors in both groups referred to the emotions experienced as part of their workup: stress (in the event of delays), anxiety and emotional turbulence:

“The long time up to donation was difficult to deal with. The ups and downs between tests, seemingly endless mountains to climb, with quite long periods of no communication in between. I felt I had to push the process along and meanwhile my life was on hold. I wanted to be available for any tests, not to delay things”
(UKD 060)

“...this period was stressful...” (UKD 090)

“The process did increase my anxiety level which I cannot explain; perhaps the fear of failing the tests or the kidney not working. I had never experienced it before...” (UKD 101)

Some SKDs, not all of whom would have received a psychological assessment, felt they may have benefited from additional psychological input prior to surgery. This is in stark contrast to the UKD group, many of whom have previously described the psychological assessment as overly intrusive:

“With respect to the pre-surgery process, I think it would be helpful to have some counselling built in as a standard aspect of the preparation process” (SKD 104)
"It would have been helpful to have someone neutral to speak to about the "emotional rollercoaster" - hope, fear, and managing the high level of emotion before, during and immediately after" (SKD 104)

Both groups highlighted the potential benefits of support and advice from other donors:

“...there should be a provision to get the contact details of donors who are willing to be contacted... to get advice on organ donation and to share the experience...” (SKD 025)

"I want to be part of a pre-donation support team: my personal experience could be of great value to people considering a donation" (UKD 049)

Inpatient experience
Both positive and negative experiences were reflected upon. Positive statements were related to the care received from staff at the time of donation:

“I cannot fault the care I received leading up to during and after my donation” (UKD 018)

“I have been treated very well by all staff, my stay in hospital, food, all the support. They are a great team” (UKD 139)

“I would like to say that my experience of the care and attention by doctors and nurses while I was in hospital was fantastic” (SKD 003)

“The staff [were] outstanding” (SKD 044)

Negative comments related to bed shortages, understaffing, the conduct of other patients and no contact with the staff who the donor had encountered during their workup:

“[It was] a nightmare - over a twelve hour wait for a bed on arrival the day before operation; A hellish recovery in an understaffed intensive care unit; Overworked, stressed nursing staff with malfunctioning equipment and inept chart keeping, seriously compromised my recovery. [I] self-discharged under duress [and had] expected a better standard of care” (UKD 048)

“[I] felt like I was "forgotten"... I sat for a good 5 hours [waiting for a bed], anxiety and nervousness growing all the time. It was having a chat with one nurse who restored my confidence and reminded me of the reason why I was there, that enabled me to go through with it” (SKD 130)

“I had no contact whatsoever with my "Transplant Co-ordinator" or my surgeon, despite being told they would be there to answer any questions I may have, before or after my operation” (UKD 131)
“The night before the transplant was dire... The outrageous behaviour of other patients was an issue too” (SKD 044)

Some UKDs expanded on the complications they had suffered following their surgery:

“I had a stroke while under the anaesthetic. I have lost about 25% of my sight and clarity of thought sometimes... but I would still donate again” (UKD 100)

“I am still having some investigations as I have a 10cm lump on my right side near the big scar which they are looking into... it did not heal right” (UKD 148)

Post-operative Recovery

Those donors who commented on the recovery after discharge from hospital were predominantly negative. Donors felt they received inadequate or inconsistent discharge information and minimal aftercare. For some, this led to feelings of abandonment:

“A little more contact from the hospital, i.e. after care would be nice... It feels like you’ve done your bit now go!” (UKD 074)

“... 2 weeks after donating I became unwell. No one seemed that interested... [I] felt abandoned by the medical profession. I have read the stuff about people feeling low after donation, “no longer the centre of attention”... I do feel conned. I don’t regret donating - but I thought my health might be important - just a little!” (UKD 107)

“All contact with my transplant co-ordinator ceased as soon as I’d had my op. I felt a bit let down and abandoned” (UKD 009)

“There needs to be more consistent information... the amount of water you should drink... the risks of lifting / bending... more information on diet...” (SKD 013)

“Post-operative advice should be more emphatic and precise concerning when a patient should re-engage with normal physical activity after [the] operation” (UKD 003)

Financial reimbursement was also an issue for both groups:

“I received less than my (legitimate) claim and I know others who have waited months for reimbursement of work related expenses” (UKD 053)

“I didn’t expect or want to gain financially but I didn’t expect to lose money” (UKD 009)

“Had a bit of an issue obtaining financial compensation from the relevant agency...” (SKD 119)
UKDs who had experienced issues with reimbursement or cosmetic complications, which were not rectifiable with NHS funding, reflected on the financial benefits of transplantation versus dialysis:

“At a purely financial level, the cost saving to the NHS of living donation vs. dialysis is considerable” (UKD 090)

“Given the financial advantage to the NHS of transplants, this is regrettable” (UKD 053)

“My one big area of disappointment is that the NHS has not been prepared to fund corrective surgery to my donor nephrectomy wound… I have [it] as a result of giving an organ to help another person, but also saving the NHS money and resources” (UKD 116)

Additionally the UKD group experienced issues related to the convalescence period allowed by employers. Those working for the NHS in particular were not allowed to take sick leave and were told to use their annual leave for convalescence:

“… Unfortunately I was not awarded sick leave, despite being [working for the] NHS and had to use my annual leave and got time off partly by not getting paid for the days I was off duty. If this can happen to a doctor working in the NHS then what chance would someone else have? This was the only disappointment I have experienced after and just before my donation” (UKD 004)

“I work for the NHS [and] my boss didn't let me have any time off (including the day of the operation)…” (UKD 060)

Theme 3: Attitudes of others
Comments related to the attitudes of others were noted only by the UKD group.

Family and friends
UKDs reported telling very few people about their donation for fear of being dissuaded. A minority had not discussed their intention with loved ones until encouraged or told to do so by the transplant team:

“I told very few people prior to my donation. I felt they would try and dissuade me. I have mentioned it to some people subsequently” (UKD 007)

“I told very few (3) people that I was donating as when each one told me I'd lost the plot I became a little discouraged” (UKD 140)

“I never expected to pass the selection process and so I applied without my wife's knowledge. My co-ordinator advised I included [her]…” (UKD 057)
“It was a very single minded decision. Ideally I would not have let anyone else know. I had to tell my partner...” (UKD 013)

UKDs encountered arguments and disagreements with their loved ones who had questioned their reasons for donating and expressed concerns for their wellbeing. UKDs were not ultimately dissuaded by these comments but had at times considered withdrawing:

“I had MASSIVE rows with the most important person in my life. The basis for these rows was that I was putting myself in harm’s way, I might die, I might be ill for ages, sometime in the future my remaining kidney might conk out... I came VERY close to withdrawing...” (UKD 140)

“[My partner] was very against it. He articulated several reasons but I think it ultimately (understandably) was anxiety over the risks posed to both my physical and psychological health” (UKD 013)

“Regarding friends and family, most supported my decision with one exception who strongly opposed it. This did not affect my decision at all” (UKD 045)

The transplant team

Encounters with members of the transplant team were noted by the UKDs and also varied. Many reflected on a positive experience, having received excellent care throughout their donation experience:

“I have met some very kind and caring personnel during this process” (UKD 138)

“The support and information given by the transplant team was exceptional” (UKD 033)

“I was made to feel very special” (UKD 115)

“From the start to the very end of my donation I can honestly say I have never before been treated with such kindness, courtesy and professionalism” (UKD 111)

Negative experiences were also encountered during the workup process and were related to the attitudes and opinions of those assessing the UKDs’ suitability. These included psychiatrists, independent assessors and members of the surgical team:

“At one appointment a surgeon said he couldn’t understand why anyone would want to be an altruistic donor!” (UKD 059)

“The first psychiatrist I saw decided that I was doing it for the wrong reasons... I simply thought it was a way to help someone on dialysis get a better life” (UKD 016)
“I found the chaplain that I saw very inappropriate... In fact, on the edge of being biased. She made me feel as what I was doing is not right! My decision should not be based on any religious beliefs at all! If I was not a strong willed person this could so easily [have] gone a different way” (UKD 125)

“On reflection, whilst I was not expecting any special treatment I have been left with a rather uncomfortable feeling that I was regarded as a bit of a freak or an unnecessary burden by some of the hospital staff. At the moment I would find it hard to recommend altruistic donation to anyone else” (UKD 092)

Further analysis of UKDs’ experiences demonstrated that those who reported a positive relationship with their transplant team had donated more recently and also donated in a centre where UKD was more commonly performed. Negative experiences were not found to be centre specific but were related to the year in which the donation took place, those donating longer ago experiencing more negative attitudes.

Theme 4: The recipient
Reflection on the impact of donation on the recipient was understandably different between the two groups. The SKD group noted the positive effects on their recipient's life following transplantation and the consequential positive impact on themselves and rest of the family:

“I gave a kidney to my daughter aged 20 months. This meant I no longer had to connect her to a dialysis machine every night... [she] has now started school and you can't tell at all that she was born with 1% kidney function” (SKD 050)

“My son's life, our life as a family has been transformed in such a positive way. I feel so very proud and appreciative to see him growing, developing, eating, his social skills... I feel privileged to see this” (SKD 027)

“It has improved our lives tremendously and I am glad I did it for that reason” (SKD 033)

The possibility of complications and the associated emotions were also contemplated:

“Not sure how I would have felt if recipient had "rejected" after op. Also not sure how I will feel if / when another transplant is needed” (SKD 083)

“There is always a concern that he may one day have rejection, but so far after 6 years his kidney is still excellent” (SKD 027)

SKD recipients had encountered complications following transplantation including rejection and death:
“Sadly my recipient (husband) died following complications with the transplant...” (SKD 018)

“I was part of a paired donation... My sister is not doing too well, but I take comfort thinking that statistically my actual recipient IS probably doing well” (SKD 070)

The UKD group reflected on the amount of contact they had had with their recipient and, as demonstrated in the quantitative component of this study, this varied considerably. UKDs had both written to their recipient and failed to receive a reply, and vice versa. Non-reciprocated contact was associated with negative emotions:

“[I] received thank you letter. I did not respond.” (UKD 014)

“I wrote a letter which was passed to my recipient by my coordinator but received no reply. I would have liked a reply even if it was just to say they didn’t want any contact with me. To get nothing in return left me feeling a bit ‘flat’” (UKD 036)

“I wrote, through my coordinator, a letter that I wished to be passed to my recipient... I still have no idea if the letter was passed [on]... I feel a little upset about this. I really would like to know how the man is getting on with his life and despite the fact that he may have passed/died through complications...” (UKD 019)

Many UKDs were unaware that they could make enquiries about their recipient after the immediate post-operative period:

“I didn’t know that I could ask to meet them!” (UKD 027)

UKDs were inquisitive about their recipients, however accepted their decision not to get in touch. Many wished their recipient well and hoped that they continued to enjoy their transplanted kidney:

“It would have been nice to have had more information on the outcome of my donation but I feel it is very important that any contact from the recipient should only happen if they wish it” (UKD 115)

“...it is important that the recipient should not feel obligated to make contact” (UKD 057)

“I very much hope my recipient is healthy and well and enjoying life” (UKD 048)

“Deep down I would like to meet them. I don’t think I will ask to meet them initially however if the request comes from them then I will be very happy to
accept. If it never happens then I am still happy I was able to help and wish them a long happy enjoyable life” (UKD 133)

Some UKDs received additional correspondence from their recipient and have continued contact, whereas others had come to an end:

“...the recipient of my kidney was 24 years old. She has done well since. I write a card on the July anniversary. She sends a card each Christmas. On the 2nd anniversary she married and sent me a photo with her usual Christmas card. The kidney has clearly turned her life around. I feel the contact through the respective co-ordinators is a very strong part of the structure” (UKD 057)

“I was really surprised and pleased to receive flowers and cards from the person who received my kidney. This continued at Christmas and on anniversaries for a couple of years. This has since stopped and although I send a card each Christmas I get no response...I would like to have the reassurance that [he] is still alive and well by receiving some news. But then again I remind myself that maybe he just wants to get on with his life and not keep looking back...” (UKD 006)

UKDs had varying opinions on how much information they wished to receive about their recipient, before and after transplantation:

“If my recipient is a latter day George Best, I’d rather not know it. I don’t ask who is receiving my blood...” (UKD 140)

“I do not want to know who the recipient is because then it would be about specific relationship (possibly) thus undermining "altruism”” (UKD 001)

“Looking back I now think I would only want to know the minimum information... The more I know about the person the more I feel a connection and the whole point of donating to a stranger was I did not want any emotional connection [however] no information at all would have left me wondering which would not be good” (UKD 043)

UKDs also varied on how much they would like to know in the event of a complication:

“I found out soon after my donation that the operation wasn't successful which saddened me somewhat” (UKD 042)

“I sometimes think too much information is given to donors especially if the kidney failed to take in the recipient. I am not sure donors should be told that” (UKD 043)

Theme 5: Reflection on the donation experience

Effect on self

Both groups of donors reflected on the donation process and how it had affected them:
"I found the whole experience fascinating and rewarding" (UKD 140)

"It was all a very positive experience" (UKD 128)

"... [it] was a positive experience which I willingly took part in and would do again - no doubt at all" (SKD 054)

"[The] best thing I have ever done... the outcome of my son leading a normal life ... priceless" (SKD 101)

Many reported positive emotions associated with donating. For the SKD group these were closely associated with the positive impact the transplant had had on their recipient. For the UKD group this was associated with the act of donating and the positive impact the transplant had had on the recipient (where communication had taken place):

"Having the opportunity to donate a kidney to my husband was a wonderful and empowering opportunity to do something that could improve his health and quality of life" (SKD 104)

"Even more so now where every day, he grows in confidence and his health is constantly improving. The time before the operation now seems like a distant nightmare. I now have my brother back and I am proud to say that I partly made that happen" (SKD 130)

"I feel so very proud and appreciative" (SKD 027)

"Being a living kidney donor has been one of the happiest and most enjoyable and rewarding experiences of my life. I wish that I could do it again" (UKD 028)

"I have found the action of giving an organ immensely satisfying. Not for grandiose intentions but a real and positive act to help another...” (UKD 001)

"I had high self-esteem pre-op but constant praise has obviously had an effect" (UKD 126)

As noted above in both the quantitative answers and within theme 1 (Motivation to donate), UKDs regarded their donation as a simple, straightforward act that would have minimal impact on them with maximal benefit to another:

"I was amazed at how simple donating my kidney was...I still can’t believe how easy it was to save someone else’s life and if I could do it again, I would” (UKD 088)

"There is an immediacy and simplicity in donating a kidney. It is pragmatic...” (UKD 001)
UKDs expressed thanks to the NHS and transplant teams for donation being possible and for being allowed to donate:

“I regard it as a great privilege to have the opportunity to donate and I would like to commend all [those] who made it possible” (UKD 045)

Some donors additionally reflected on how donation had affected other aspects of their lives, such as contextualising other life events and appreciating their health:

“My experience has taught me not to worry or get upset over minor issues… I value how precious life is far more now. I appreciate my health - sitting amongst the crowded kidney clinic waiting area was very humbling” (SKD 018)

“Other issues in my life don’t matter to me as much as they did before” (SKD 027)

**Regret**

Unfortunately no donor who had expressed regret in the quantitative answers elaborated further on their reasons in the free text space. Instead, donors from both group elaborated on how they would do it again if they were able to, even in the event of life-changing complications. Many were hopeful that more people would donate and were keen to encourage others:

“I have absolutely no regrets in donating my kidney” (UKD 039)

“If asked would I do it again, I have no hesitation in shouting "Yes!"” (UKD 086)

“I had a stroke while under the anaesthetic… but I would still donate again” (UKD 100)

“It was my son I gave my kidney to and I do it again if needed for anyone” (SKD 041)

“[I] would do again - no doubt at all” (SKD 054)

In the event of a disappointing or troublesome recovery, some donors were still not regretful about their decision to donate. However some UKDs felt that they would not be in a position to encourage others due to the negative experience they had had:

“I do not have any regrets donating my kidney as this was the right path for my late husband and I” (SKD 018)

“Although I have never regretted my decision to donate I do honestly feel I cannot say I can encourage anyone else as my experience was so negative” (UKD 048)
“At the moment I would find it hard to recommend altruistic donation to anyone else” (UKD 092)

Summary of Framework Analysis
Thematic analysis of the free-text answers has provided further insight into the motivations and characteristics of the UKD sample. UKDs are highly motivated individuals who do not perceive their donation to be significant undertaking when considering the benefits to the recipient. Donors in both groups had a range of positive and negative experiences before, during and after their donation. UKDs had additional issues relating to prolonged workup and negative attitudes of transplant professionals. UKDs also encountered more familial conflicts; which in part explains some of the social support findings from the quantitative component of the study. Family members of UKDs did not object to donation in principle, but questioned the reasoning behind the desire to donate and expressed concern related to the risks. Reflection upon the donation by both groups was very positive, with many commenting how gratifying the process had been. Unfortunately no additional information about why some donors had expressed regret was divulged.

Discussion
This study is the largest study of unspecified donors that has ever been conducted, both in terms of its sample size and the range of questions and psychosocial outcome measures used. It is the only study that compares those who have donated a kidney entirely anonymously to a stranger with those who have donated a kidney to a loved one. It is also the only study that has attempted to capture data from a consecutive, nationwide sample of UKDs where every individual who has donated since the scheme began was invited to participate.

The main findings of this study are that there is no significant difference in psychosocial or physical outcomes between UKDs and SKDs. Despite experiencing negative views from the transplant community, UKDs appear to be highly motivated individuals who, on self-report measures, recover from surgery more quickly than SKDs. UKDs are motivated by a desire to help others and are more likely to engage in other forms of altruistic behaviour. There is no difference in levels of regret between the two groups. Communication from the recipient is welcomed, however very few UKDs desire formal contact with their recipient.
Psychological symptoms of stress, anxiety, distress and depression were equivalent between the two groups. This demonstrates that there is no negative psychological impact following UKD when compared to SKD, both for those who have recently donated and those who donated some years previously. Similarly, levels of wellbeing, life satisfaction, self-esteem and optimism were also equivalent. This demonstrates that there is no significant difference in how UKDs feel about their quality of life and towards themselves. As discussed previously, the body of evidence in support of UKD is limited. The only study with a similar design to this study is by Rodrigue et al (Rodrigue et al., 2011) who also demonstrated no difference between SKDs and a mixed sample of UKDs (including those donating completely anonymously as in this study and “directed altruistic donors”, who donate to a named individual). However, the sample size of purely anonymous UKDs was very small (19 donors) and only two validated questionnaires were used. This study is able to provide the transplant community with the most convincing evidence to date that UKDs and SKDs have equivalent psychological outcomes after donation. All UKDs in this sample would have received a mental health assessment prior to donation and although it is not possible to know how those who were screened out would have fared had they been allowed to donate, one can be reassured that those who have been allowed to donate do well post-operatively.

Interestingly, what is perhaps more surprising is why the SKD group did not have superior results to the UKD group. One may hypothesize that there would be an additional psychological benefit to SKDs from seeing their recipient well and a potential benefit from improvements in their own lives as a secondary positive outcome. By initiating the donation process and by having no intended recipient, UKDs face no duress or coercion and participate freely. This cannot always be said for the SKD group who may face familial pressures to donate and who subsequently may find it very difficult to withdraw (Valapour et al., 2011). Perhaps counterintuitively, the SKD group would not have received the same level of scrutiny in terms of their motivations, expectations and anticipated outcomes as the UKDs because their respective transplant teams would have assumed that they were donating for bone fide reasons. The SKD group would also only have been reviewed by a psychiatrist or psychologist if clinically indicated, rather than as a mandatory assessment. One explanation for the equivalent outcomes demonstrated in this study may be a combination of these factors; poor motivations, unrealistic expectations, unrealistic
anticipated outcomes and sub-clinical, unidentified psychological pathology. In addition, the SKDs may have experienced suboptimal recipient outcomes, loss of the kidney or death of their recipient. A prospective study would provide a definitive answer to these questions, as it would be important to understand the change that occurs before and after donation in both groups, rather than at a single time point.

There were some social differences demonstrated between the two groups. A lower level of social support in the UKD group, both generally and for donation, was demonstrated in the unadjusted statistical analysis of the validated Perceived Social Support questionnaire, the donation-specific questions and in the thematic analysis of the free text. Lower social support and familial objections within the context of UKD have been identified in all other studies, both quantitative and qualitative. Reduced social support in this sample of UKDs can, in part, be explained by the free text answers. The families of this sample UKDs did not appear to object to living donation per se, but were understandably concerned for the donor’s welfare. They questioned the reasons for wanting to donate and why UKDs wished to subject themselves to the risks of surgery for someone they did not know, yet they did not appear to actively or forcefully discourage the UKD from donating. Anecdotal reports from Guy’s Hospital and the Queen Alexandra Hospital in Portsmouth (the largest UKD centre in the UK) have shown that a key reason for pre-operative UKDs withdrawing from the process prior to donation is active discouragement from a family member. It is possible that those potential UKDs whose families were very against donation and who actively dissuaded them from donating did not go on to donate and are therefore not represented in this sample.

It should be noted that questions relating to the donors’ motivations and their willingness to accept the risks of surgery for a stranger are not unique to family members, but are the same questions asked by members of the transplant community. Fear associated with surgical risks are understandable and are likely to be intensified when the procedure is deemed less than absolutely necessary. In contrast, the families and friends of SKDs were likely to be more supportive of donation because the need for a kidney would have been immediately obvious, thereby making the donation more of a necessity rather than a choice. Although not seen in this study, reduced social support has previously been shown to be associated with inferior post-operative psychosocial outcomes in UKDs (Massey et al., 2010).
In addition to reduced social support at home, some UKDs also experienced negative views from the transplant community. They felt as though it had been assumed that they had an underlying psychopathological reason for wanting to donate until proven otherwise. The transplant community's cynicism was reflected in the qualitative study by Clarke et al and the findings from this study not only highlight the uncertainty within the UK transplant community towards UKD, but the inability of the transplant community to conceal it. One could argue that comments such as “[I don’t] understand why anyone would want to be an altruistic donor” are a reflection of the personal values and standards held by particular individuals, who then are subsequently influenced by these when making professional decisions.

Additionally, UKDs were also more commonly subjected to inexplicable delays and although the reasons for this are unclear, this is perhaps a reflection of two things. Firstly, this may further demonstrate uncertainty within the transplant community with regard to how best to manage these donors and as a result, UKDs may require more lengthy discussion between different team members. Secondly, this may demonstrate an informal way of testing how determined a particular donor is to donate (i.e. that it needs to be driven by the donor rather than the transplant team) and it is this latter view that is held by some UKDs within this sample. Additional comments from UKDs who worked within the NHS and who encountered difficulties in taking time off to convalesce add further weight to the negativity that some UKDs have experienced from the health service.

The physical component of the SF12 and a comparison of clinical outcome data have demonstrated equivalent physical outcomes between UKDs and SKDs. Two papers have described equivalent physical outcomes between the groups (Morrissey et al., 2005, Griffin and Morton, 2011) but both report very small numbers (18 UKDs and 17 UKDs, respectively) from single centres and neither have used a validated measure completed by the donors themselves. This study provides the largest comparison of physical outcomes between UKDs and SKDs and is the first to report outcome data from a national sample of UKDs. This study provides the most convincing evidence to date that UKD selection on physical parameters is equivalent and appropriate, and is also the first to demonstrate a significantly faster subjective recovery in UKDs. This is despite the UKDs being significantly older by an average of 10 years. The average return to work for UKDs is 4-6 weeks vs. 6-12 weeks, the average return to driving is
<4 weeks vs. 6-12 weeks and UKDs report feeling back to normal much quicker (6 weeks vs. 12 weeks). This difference in subjective outcomes may provide additional insight into how highly motivated these donors are towards donation and their subsequent recovery or may be reflection of additional physical demands placed on recovering SKDs who may also provide care for their recipient. The multiplicity of roles and the negative impact this has on recovery from living donor surgery, especially in women, is well documented (Tong et al., 2012a).

The total number of donor reported and NHSBT recorded complications were not significantly different between the two groups (UKD 33.6% vs. SKD 35.0%; p=0.845). However, the rate of overall complications was higher than the 15% quoted in the living donor literature (Wolters and Vowinkel, 2012, Hadjianastassiou et al., 2007). This increase may due to donor misinterpretation or a difference in opinion between doctors and donors as to what is classed as a surgical complication. In support of this hypothesis is the rate of major morbidity (UKD 4.5% vs. SKD 1.25%; p=0.310) which was obtained from objectively recorded data from NHSBT records (UKDs) and medical records (SKDs). These rates are much more keeping with the 5% quoted in the same papers listed above. Presence of complications, readmission to hospital and re-operation were not associated with a significant difference in any of the psychosocial factors measured in the UKD group. Higher incidences of complications were also not present in the group of donors who regretted donating. The finding of post-operative complications being associated with lower wellbeing in the SKD group is difficult to interpret. The types of complications described were less severe than in the UKD group and ought to have resolved by the time the study took place, especially if a second operation had been performed. It is possible that regular contact with their recipient provides a SKD with a constant reminder of donation and the associated problems which occurred.

The positive feelings towards donation are supported by the low levels of regret (4UKDs (3.7%) vs. 6 SKDs (7.5%); p=0.078). The rate of regret is comparatively low within the UKD group (Rodrique et al., 2011), but is comparatively high in the SKD group (previously quoted as <1%) (Fehrman-Ekholm et al., 2000). It is unclear from the Fehrman-Ekholm study exactly how regret was elicited, whether donors were asked outright and whether the questionnaire used were validated. The reasons for regret in this study are unclear as further analysis did not reveal any explanations
within the free text answers and psychosocial outcomes in those regretting their
donation were not significantly different to those that did not regret. One may
hypothesise that a poor recipient outcomes or a poor post-operative experience may
be influential, such as those highlighted by some donors in this study (i.e. minimal
aftercare, inconsistent information and lack of contact with their donor co-ordinator,
which subsequently led to feelings of abandonment). Due to the rareness of UKDs in
some centres it is possible UKDs were treated differently to the SKD group, who were
all recruited from a high-volume living donor centre. In centres where UKD is an
exceptional occurrence, the living donor team and ward staff may have been more
attentive in the post-operative period, leading to fewer negative post-operative
experiences. Another hypothesis could be that the question was misinterpreted, which
is feasible given that it was a negatively phrased question imbedded amongst
predominantly positively phrased questions. In support of this hypothesis are some of
the incongruent free text answers provided by some of the UKDs who were found to
have demonstrated regret (i.e. “I wish that I could do it again”; “If asked would I do it
again, I have no hesitation in shouting “Yes!””).

Less than half in each group felt that donating had increased their self-esteem, a
concept not previously measured in a UKD sample. Although no normal scores are
available for a UK age-matched population, both UKDs and SKDs scored towards the
upper end of the Rosenberg self-esteem scale (maximum score = 30; UKD 22.1 vs. SKD
23.2; p>0.05). Increased self-esteem following SKD has previously been demonstrated
in donor populations (Morrissette et al., 2005) but it is essential that future work aims to
capture self-perception or self-esteem data, both before and after donation in order to
fully understand whether a change does take place.

When considering the primary concerns most commonly voiced by the transplant
community regarding the motivations behind UKD, the findings of this study provide
further reassurance. Those who are sceptical about UKD commonly believe UKDs are
motivated by an underlying psychopathology or an unhealthy religious view. This
study has demonstrated that religion is rarely cited as a motive for donation and that
UKDs are driven by a desire to help others and a belief that the benefits to the recipient
outweigh the risks of surgery. This study provides quantitative evidence in support of
the qualitative study performed by Clarke et al, which showed that donation is
consistent with a belief system in which there is a deep sense of social responsibility
and where UKD is seen as a natural extension of this. The statistically higher rates of altruistic behaviours in the UKD group (including blood donation, bone marrow donation, organ donor registration, volunteer work and charitable donations) are additionally supportive of these findings. Although other studies have looked at altruistic behaviours in UKDs (and have achieved similar results) (Massey et al., 2010, Rodrigue et al., 2011), this is the first study that has objectively measured personality type. This study has shown that there is no difference in personality type between UKDs and SKDs, which alongside the findings described above, provides further evidence in support of an altruistic belief system as the primary motivating factor.

The other concern commonly voiced by the transplant community is the view that UKDs wish to donate in order to build a relationship with their recipient that is lacking in their own personal life. This study demonstrates that this is not the case as only 2 donor-recipient pairs had met in person. The rate of communication between UKDs and their recipients, where reported in the literature, ranges from 21% to 85% (Massey et al., 2010, Rodrigue et al., 2011) and UKDs’ attitudes towards the desire for future contact in this study is similarly varied. 49.5% of UKDs in this sample had received a card or letter from their recipient. Almost two thirds of this sample had found out what had happened to the recipient following their donation and a small number (2 donors) had experienced some regret at this knowledge. Similar rates of negative findings associated with recipient contact have been found in the studies referenced above.

Of those UKDs who had not heard from their recipient following the transplant, the majority (87.3%) had wanted some acknowledgement of their donation. Further elaboration within the free text answers highlights that although many UKDs do not wish to meet their recipient, on-going reassurance about their wellbeing would be welcomed. The desire to seek information may be a way to gain further reassurance that the donation was not only a good deed in itself, but also one which resulted in the desired outcome for the recipient. UKDs may therefore wish to use this information as a substitute for seeing the benefits in person. Whereas SKDs are able to visualise the outcome, UKDs must speculate it. It is likely that the equivalence in psychosocial outcome stems from this; that is, both groups benefit from having done a good deed and both groups benefit from the recipient outcome, one which is visualised (SKDs) and one which is speculated (UKDs). UKDs differed in how much they wanted to know
and on whether negative outcomes should be reported back to the donor. For the inquisitive UKDs, the quest for information is a means by which to quantify and add some degree of reality to the speculated outcome. Those who wish to know little of their recipient may simply be satisfied with the idea that they have done a good deed or conversely may not want to risk their donation being tarnished by a negative outcome. The concept of recipient idealisation has been discussed within the context of UKD as an argument for maintaining anonymity after donation (Mamode et al., 2013) for this very reason (i.e. to protect the donor).

This study is limited by its retrospective design and regional SKD comparison group. No comparison can be made to baseline, pre-operative psychosocial scores and the time since donation is broad (3 months to 5 years). There may be some selection bias within the sample with fewer responses from those with negative experiences or those with poor psychosocial outcomes. In addition, it was also not possible to establish where (i.e. which transplant centre) the UKD non-responders were from and their reasons for not wishing to participate. However, the data provided by NHSBT has shown that all UKDs are still alive and none have experienced any major complications that would stop them from participating. A further limitation is the size of the SKD comparison group which resulted in low statistical power to detect adverse outcomes, such as regret. A nationwide prospective study is needed to further evaluate some of these issues and should allow for a more in-depth analysis of the impact of donation by comparing pre and post-operative scores. Finally, this study investigated the largest cohort of available UKDs at the time, which encompassed the first 5 years in the history of the UKD programme in the UK. The speed with which the programme has developed has created a steep learning curve for healthcare professionals. Current practice differs significantly from the historical perspective; UKD has moved from exceptional to regular practice in a relatively short timeframe. The findings of this study are inevitably influenced by the change in approach to UKDs by the transplant community.

When looking to the future, UKD is becoming increasingly popular in the UK with a threefold increase in the number of donors approved by the HTA in 2011-12 when compared with the previous year. Completion of a mandatory mental health assessment has been removed by the HTA but currently remains the agreed clinical standard. This study has demonstrated that a mental health history does not prohibit a UKD from donating and nor does it increase the likelihood of an adverse post-operative
outcome. This sample of UKDs would have all undergone a mental health assessment, some of whom found it to be the most concerning part of their workup, possibly triggering feelings of vulnerability (Clarke et al., 2013). There is no data available regarding the sensitivity and specificity of this assessment or whether it can be safely removed, yet there are still large numbers of potential UKDs who are screened out for a variety of psychosocial reasons (Nadkarni et al., 2012). Given the positive psychosocial outcomes reported from this study and the reliance on positive outcomes to further expand the UKD programme, it may be prudent for mental health assessments to remain best practice until further evidence is available.

Conclusions

This study has demonstrated that unspecified kidney donors have sincere motivations and comparable physical and psychosocial outcomes to specified kidney donors. There is little regret and very little contact between donors and recipients. These favourable outcomes may be, in part, due to the rigorous workup process which includes a mental health assessment. These findings are encouraging and support continued and safe expansion of the UK programme with the expectation of favourable outcomes.

Due to the increasing numbers of UKDs presenting to transplant centres and proceeding with donation, the UK transplant community is in a position where, for the first time, a prospective longitudinal study is feasible. A prospective study is necessary to further develop the key findings demonstrated here and to determine whether UKDs and SKDs are as equivalent pre-donation as they are post-donation. Additional work is also required to investigate the views of the transplant community and UKDs’ social networks to determine whether, in some cases, negative views may be forming a barrier to donation.
Chapter 8

Thesis summary, Recommendations for Future Research and Recommendations for Clinical Practice

Thesis summary
This thesis has provided an assessment of psychological outcomes after living kidney donation. The thesis began in chapter 1 with an outline of the moral and ethical challenges inherent to living donation and provided an explanation for why being able to measure psychosocial benefit is important within this context. The moral dilemma within living donation is that one inflicts a physical harm on an individual without there being a resultant physical benefit. In order to make living donation morally justifiable there must be a psychosocial benefit to the donor. As was detailed in chapter 2, there are very few studies, and therefore very little quantitative data, that provide sufficient, good quality evidence in support of there being a psychosocial benefit to the donor after donation has taken place.

The aims of this thesis were to attempt to measure psychosocial benefit after donation and, if possible, to identify which factors may be associated with both positive and negative post-operative outcomes. This was conducted via a quantitative longitudinal study which measured a range of psychosocial factors pre-operatively and at 3 and 12 months post-operatively. Prior to this study being conducted a qualitative study was performed in order to explore the field of living donation in more detail and to help identify which psychosocial and donor-specific factors should be measured as part of the longitudinal study.

Chapter 3 of the thesis outlined the rationale, methods, results and conclusions of the qualitative study. This large piece of work provided a valuable opportunity to gain insight into the factors affecting living kidney donors. The outcomes of this study upheld the findings of other qualitative studies which had previously described the issues related to living donation as being complex and multifaceted. As well as generating a number of hypotheses for the longitudinal study, this qualitative study also guided the structure of the questionnaire that was used; both through the selection of validated psychosocial outcome measures and the writing of new questions. In retrospect, the qualitative study also helped provide explanations for some of the findings from the quantitative study.
Chapters 4 and 5 outlined the methodology and results of the longitudinal quantitative study. The most significant finding was the failure to demonstrate a psychosocial benefit after donation. I had hypothesised that wellbeing, life satisfaction, self-esteem and social comparison scores would increase after donation, that distress, depression, stress and anxiety would decrease after donation and that physical health-related quality of life, social support and optimism would remain the same at 12 months after donation.

This study failed to demonstrate a statistically significant improvement in wellbeing, life satisfaction, self-esteem, social comparison, distress, depression, stress and anxiety after donation. As is detailed in chapter 5, the differences in scores between the pre-operative, 3 month and 12 month scores were very small and, for the majority of questionnaires, was neither clinically nor statistically significant. An unexpected finding was the steady decrease in social support scores after donation and the failure of health-related quality of life scores to return to baseline by 12 months. The differences in social support and health-related quality of life were again very small and although they were statistically significant, they would be unlikely to translate into a clinically significant difference. This study was therefore unable to demonstrate any objective psychosocial benefit from donating a kidney.

This study provides the most comprehensive quantitative assessment of living kidney donors that has ever been attempted. Never before have so many validated questionnaires been used to prospectively measure psychosocial outcomes in living kidney donors. The failure of this study to demonstrate a benefit therefore has potentially significant implications for the practice of living kidney donation. When returning to the moral dilemma discussed in chapter 1, one is now faced with the question as to whether living kidney donation should be allowed to continue. Based on the findings of this study, one cannot confidently say that living kidney donation is morally justifiable through a psychosocial benefit to the donor. The transplant community are therefore subjecting a significant number of healthy individuals to an operation that they do not need and one that they do not appear to objectively benefit from.

Whilst the findings of this study are valid and can legitimately question the practice of living kidney donation, it is important to reflect on the limitations of the longitudinal
study and what this study has failed to measure. Whilst one has not been able to
demonstrate a psychosocial benefit to living kidney donation, one cannot confidently
say what would have happened to these individuals had they not been able to donate.

Had a living donation not taken place it is likely that some of the recipients would have
received a transplant from the deceased donor waiting list, some would remain on the
waiting list and some would have died. It is impossible to know what impact these 3
possible outcomes would have had on the individuals who participated in this study
and whether these outcomes would have had a negative psychosocial effect. Through
the qualitative study this thesis has highlighted how emotionally distressing it is to
have a loved one with renal failure. Donation has provided each of these individuals an
opportunity to not only ease the suffering experienced by their recipient, but also their
own distress. As is well documented in the literature, the majority of the donors
sampled in this thesis made their decision to donate instantly and were not influenced
by the risks of the procedure. This either demonstrates a strong desire to help a loved
one who is in need, or a strong desire to make life better for the recipient, themselves
and for those around them. If one was able to demonstrate a decline in psychosocial
health from not being able to donate, the results of this quantitative study would take
on a different significance.

Additionally, one of the limitations of the quantitative study was the relatively narrow
time period over which psychosocial factors were measured. Before a living kidney
donation takes place there is likely to be a minimum of 6 months needed to complete
the workup process, on top of which is the period of time before that when the
recipient was unwell. The period of time after donation is also considerable, as a living
donor transplant kidney is expected to last between 15 and 20 years. What one cannot
be certain of is how the results described in this thesis fit into this much broader
timeframe. Although no significant changes have been demonstrated in the
quantitative study, this may represent a period of relative emotional stability within
the donor’s life. It is impossible to say whether the pre-operative score provides a true
baseline for that individual, whether the score is better or worse than when the
recipient was well, or whether it is different from when they first presented as a
potential donor. Similarly, it is impossible to say whether the 12 month score is a new
baseline for a particular individual, or whether scores will increase or decrease as time
goes on.
Chapter 6 of this thesis focussed on the impact of psychological stress, personality and optimism on surgical wound healing. This study utilised both a novel patient sample and a novel technique (high-resolution ultrasound) to demonstrate a negative association between stress and wound healing, and the positive influence of optimism, conscientiousness and emotional stability. A larger study is needed to allow an assessment of whether the relationship between stress, personality and wound healing has a clinical significance; for example, in the rate of infections, hernias and post-operative wound pain. This is worth investigating within the context of living kidney donation because if a clinical significance was demonstrated, it would provide a good incentive to try and reduce pre-operative stress prior to donation. Whilst this has implications for all types of surgery, it is especially significant in living kidney donors due to the fact that they are undergoing an operation for the primary aim of benefiting another person and the need to keep complications to a minimum is all the more important.

Chapter 7 of this thesis detailed the world's largest study of unspecified kidney donors. This increasingly popular practice has been embraced with caution by the transplant community due to a poor understanding of donor motivations and a lack of evidence demonstrating equivalent psychosocial outcomes to specified kidney donors. This study of 148 unspecified donors compared psychosocial outcomes with an equally sized sample of specified donors. It demonstrated that unspecified kidney donors had sincere motivations, comparable physical and psychosocial outcomes to specified kidney donors and that there was little regret.

**Implications for future research**
The next step for research in this field is a larger, national, prospective study of both specified and unspecified donors, and those who come forward as potential donors who do not go on to donate. The aims of this study would be to address the 2 key limitations of the quantitative study discussed above and the limitations of the unspecified donor study discussed in chapter 7. By broadening the timeframe over which psychosocial factors are measured one would be able to contextualise the findings of the studies performed in this thesis and also understand more about how the entire process of being a living kidney donor may impact an individual. By including those who do not go on to donate one can capture data on whether this has a negative psychosocial impact. If one finds that not donating has a negative
psychosocial impact, this would strengthen the moral argument in favour of living kidney donation.

I am a co-applicant on a successful grant application to the National Institute for Health Research Health Services and Delivery Research Programme. The funded study will commence in March 2015 and will focus primarily on comparing psychosocial outcomes between specified and unspecified kidney donors. This national study will recruit individuals from the moment they present to the transplant centre and will follow them through the living donation process. Data will be captured from those who donate, those who withdraw from the process and those who are told they cannot donate by the transplant team. Additionally, a qualitative component of the study will further investigate the views of transplant professionals towards unspecified donors and whether this is a barrier to donation in some centres. An economic analysis will also be conducted to answer the question of how much an unspecified kidney donation is worth to the NHS.

The next phase of research into the impact of stress, optimism and personality on wound healing will be a multicentre randomised control trial with substantially larger numbers and will include the specified outcomes outlined in chapter 6. Different psychological interventions designed to reduce pre-operative stress will be compared against a control group of no intervention to determine not only whether a reduction in stress affects the rate of wound healing but also whether it provides a clinical benefit to the patient. A grant application for this study is currently in progress.

**Implications for clinical practice**

This thesis has a number of implications for clinical practice. Transplant professionals should be aware that, at present, there is no conclusive quantitative evidence in support of living kidney donors benefitting psychologically from their donation. Within the context of pre-operative donor counselling, donors must be made aware that whilst the physical harm of their donation is a certainty, a corresponding psychological benefit is not. They must also be aware that, at present, there are very few indicators of who will benefit from donating and who will not.

It is therefore imperative that living kidney donors continue to undergo a thorough assessment in order to keep both the short and long-term risks of donation to a
minimum. As part of that assessment it is important to adhere to the guidelines and recommendations made by national organisations, such as the British Transplantation Society (BTS) and NHS Blood and Transplant (NHSBT). The need to conduct a mental health assessment is clearly stated within the BTS guidelines as being an “essential” part of donor workup so that “pre-existing or potential mental health issues that might arise for the prospective donor” are identified and “appropriately addressed”. This thesis has demonstrated that a large number of donors do not appear to be routinely asked about their mental health by any of the transplant professionals conducting their assessments. Whilst mental health history does not appear to have a negative impact on post-operative outcomes, pre-operatively donors with a previous history of mental health problems were found to have lower pre-operative self-esteem, lower emotional stability and lower social support. Additionally, those taking antidepressants at the time of surgery were found to have statistically significantly lower mood, physical health-related quality of life, life satisfaction, self-esteem, social support, optimism and less emotional stability; however the numbers were small (n=6) so cannot be conclusive. Donor should therefore be routinely asked about their mental health in order to flag up potential problems and to offer appropriate support. Each member of the transplant team should be equally responsible for ensuring that donors are asked these questions and are referred to psychological services if indicated.

A key finding from this thesis is the importance of donor primary caregiver status. This is important for 2 reasons. Firstly, donors who are primary caregivers have lower pre-operative psychosocial questionnaire scores than their non-primary caregiver counterparts. This is likely to be due to caregiver burden, which may cause additional issues at the time of donation principally because these donors must not only prepare themselves for a big operation but their recipient also. Every effort should therefore be made to encourage these donors to seek additional social support at the time of their donation in order not to jeopardise their own recovery.

Secondly, primary caregiver donors continue to have lower psychosocial questionnaire scores than their non-primary caregiver counterparts 12 months after donation, despite an initial improvement at 3 months. This is most likely to be due to a post-transplant euphoria that is associated with the drastic improvement in the recipient’s health and quality of life immediately after transplantation. Over a medium and long-term period this is likely to be replaced by a realisation that transplantation is a
treatment, rather than a cure for renal failure and is associated with its own complications and implications for the recipient's long term health. It is therefore important that transplant professionals do not assume that a donor no longer has any concerns or anxieties related to the transplant once it has taken place. They must also bear in mind that whilst donors may appear happy within the immediate post-operative period, this may change. Donors should therefore be provided with the opportunity to discuss their concerns related to transplantation with the transplant team; perhaps on the occasions when they attend for their annual follow up.

Similarly, it is also important for the transplant team to remember that whilst living kidney donors are fit and healthy individuals who have come forward to donate a kidney, they are also individuals who may have additional life challenges to deal with before, during and after donation. For many donors, having a loved one with renal failure is one of a number of simultaneous sources of psychological distress. Transplant professionals should be aware that there may be other issues affecting the donor at the same time as their donation and that additional advice and support to help deal with these may be required.

The qualitative study also identified other factors that may have an impact on donors, such as being the only available donor and being asked to donate. Whilst these factors did not appear to be associated with worse pre-operative questionnaire scores in the quantitative study, those affected within the qualitative study were affected significantly. I think there is a benefit in asking donors these questions pre-operatively as it may invite a discussion regarding possible feelings of entrapment and may identify the need for more psychological support.

This thesis has also provided the best evidence to date in support of unspecified kidney donation. These donors frequently have sincere motivations and comparable physical and psychosocial outcomes to specified kidney donors. These favourable outcomes may be, in part, due to the rigorous workup process which includes a mental health assessment and until more data are available, this should continue to form part of the routine pre-operative assessment of an unspecified donor. The equivalent outcomes between specified and unspecified donors should reassure the transplant community that the practice is safe and can continue to expand with the expectation of favourable outcomes.
Conclusions

In the words of Dr Joseph Murray, “As physicians motivated and educated to make sick people well, we make a basic qualitative shift in our aims when we risk the health of a well person, no matter how pure our motives”. As transplant professionals we endorse the practice of living kidney donation, which over the last 50 years has evolved from the extraordinary to the routine. Whilst it is the transplant surgeon conducting the operation that ultimately inflicts the physical harm on the donor by putting “knife to skin”, the transplant community as a whole must share the responsibility of taking adequate care of its living donors.

The pursuit of measuring psychological benefit in living kidney donors should remain a priority within the field of living donation, not only so that the programme can safely expand but also so that donors can be screened and consented appropriately. It is paramount that the legacy of a living kidney donation does not rest solely with the recipient’s graft function. It is essential that as well as minimising the physical risks of donation that we endeavour to maximise the psychosocial benefits to the donor so that they can enjoy the rest of their lives both healthy and happy.
References


Deedat, S., Kenten, C. & Morgan, M. 2013. What are effective approaches to increasing rates of organ donor registration among ethnic minority populations: a systematic review. *British Medical Journal Open, Dec 20;3(12):e003453*


Julian, L. J. 2011. Measures of anxiety: State-Trait Anxiety Inventory (STAI), Beck Anxiety Inventory (BAI), and Hospital Anxiety and Depression Scale-Anxiety (HADS-A). Arthritis Care and Research, 63 Suppl 11, S467-72.


Appendices

Appendix 1: Topic Guide for pre-operative donors

1. Introduction

2. Pathway to Donation
   - Explore how they came to being a living donor
   - Circumstances of donation
     - Recipient story
     - What has life been like since recipient has had renal failure / been on dialysis?
   - Relationship with recipient
   - Role of donor in care of recipient – What is their involvement?

3. Decision making / Risks of Surgery
   - Explore how living donation was first addressed / discussed
   - Explore potential donor pool - Why them / why not someone else
     - How do they feel about it being them?
     - What is good / bad about them donating?
   - Explore decision making process
     - Can you talk me through your decision making process?
       - Ease / difficulty
       - Instant / considered
       - Any ‘negative’ factors that were motivational
         - Expectation
         - Pressure
         - i.e. anticipated regret
       - What was the opinion of close friends / family / partner / children
   - Explore feelings towards the risks of the operation
   - Were these important?
   - Any particular concerns?

4. Expectations
   - GENERAL - Move on to consider the outcomes after surgery
     - Explore 6 month outlook
       - What are the expectations for this process? (IDEAS)
Explore concept of ‘successful’ transplant
  - Self
  - Recipient
  - Presence / absence of complications

- Have you thought about a worst case scenario? (CONCERNS)
- Regret – Is there anything that would make you regret your decision to donate?

**SELF**

- Effect on self
  - Self-perception
  - Perception of others
  - Relationship with recipient / others

- Where does donating fit in amongst the other things you have done in your life?
  - Exploring significance of donation

5. Conclusions

- Thank participant for taking part
- Invite any further comments on issues not already covered
Appendix 2: Topic Guide for post-operative donors

1. Introduction

2. Pathway to Donation
   - Explore how they came to being a living donor
   - Circumstances of donation
     - Recipient story
   - Relationship with recipient before transplantation
     - Role of donor in care of recipient prior to transplantation
   - Explore expectations of donation
     - Surgery
     - Outcome

3. Decision making / Risks of Surgery
   - Explore how Living Donation was first addressed / discussed
     - Explore retrospective feelings about this process
   - Explore potential donor pool - Why them / why not someone else
     - How did they feel about it being them? (i.e. what is good / bad about them donating?)
   - Explore decision making process
     - How easy / difficult was making the decision
       - Was the decision made instantly or thought through (i.e. moral vs. rational decision maker)
       - Was there a ‘deciding factor’?
         - What was the opinion of close friends / family / partner / children
         - Was there any pressure (positive or negative)
         - Explore anticipated regret
   - Explore feelings towards the risks of the operation
     - Were these important?

4. Donation
   - Explore donation experience
   - Explore issues around recovery – i.e. complications
     - Self, recipient
   - Explore expectations and whether these were met
5. Expectations

**GENERAL** - Move on to consider the outcomes after surgery
- Explore main ideas and expectations after donation
- Explore concept of 'successful' transplant and whether this has changed (if so, why?)
  - Self, recipient, presence / absence of complications
- Explore life since transplant occurred
  - How does this compare with beforehand?
- Explore concept of a 'successful transplant'
  - Has this been met?
- Explore anticipated effects / benefits
  - Were these met?
- Explore ongoing concerns / anxiety
- Regret – Is there anything that would make you regret your decision to donate?

**SELF**
- Effect on self: Self-perception, perception of others, relationship with recipient / others
- Where does donating fit in amongst the other things you have done in your life?
  - Exploring significance of donation

6. Conclusions
- Thank participant for taking part
- Invite any further questions / comments on issues not already covered
Thank you for agreeing to participate in our Living Kidney Donor study. This questionnaire is made up of 3 sections:

Section 1 – Quality of Life Questions
Section 2 – Your Donation
Section 3 – Questions about you

Please complete each question as best as you can. If there are any questions you would prefer not to answer, please leave them blank.

Once you have completed the questionnaire please return it to the researcher.

Should you have further any questions about the study or the questionnaire then please do not hesitate to get in touch with the research team. Our contact details are provided at the end of the Patient Information Sheet.
Section 1 – Quality of Life Questions

Instructions: Please answer the following questions on a scale of 1 to 10 (1 being the worst answer, 10 being the best).

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>How satisfied are you with your life nowadays?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>How happy did you feel yesterday?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>How anxious did you feel yesterday?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>To what extent do you feel the things you do in your life are worthwhile?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
</tr>
</tbody>
</table>

Instructions: We would like to know how you have felt about the statements below over the past few weeks. Please answer ALL the questions below by selecting the answer you think best applies to you. Remember that we want to know about present and recent health.

Have you recently...

<table>
<thead>
<tr>
<th>Question</th>
<th>Better than usual</th>
<th>Same as usual</th>
<th>Less than usual</th>
<th>Much less than usual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Been able to concentrate on whatever you're doing?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lost much sleep due to worry?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>Felt that you are playing a useful part in things?</td>
<td>More so than usual</td>
<td>Same as usual</td>
<td>Less so than usual</td>
<td>Much less useful</td>
</tr>
<tr>
<td>Felt capable of making decisions about things?</td>
<td>More so than usual</td>
<td>Same as usual</td>
<td>Less so than usual</td>
<td>Much less useful</td>
</tr>
<tr>
<td>Felt constantly under strain?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>Felt you could not overcome your difficulties?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>Been able to enjoy your normal day-to-day activities?</td>
<td>More so than usual</td>
<td>Same as usual</td>
<td>Less so than usual</td>
<td>Much less than usual</td>
</tr>
<tr>
<td>Been able to face up to your problems?</td>
<td>More so than usual</td>
<td>Same as usual</td>
<td>Less able than usual</td>
<td>Much less able</td>
</tr>
<tr>
<td>Been feeling unhappy and depressed?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>Been losing confidence in yourself?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>Been thinking of yourself as a worthless person?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>Been feeling reasonably happy, all things considered?</td>
<td>More so than usual</td>
<td>About the same as usual</td>
<td>Less so than usual</td>
<td>Much less than usual</td>
</tr>
</tbody>
</table>
**Instructions:** Over the past 2 weeks, how often have you been bothered by any of the following problems?

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not at all</th>
<th>Several days</th>
<th>More than half the days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Little interest or pleasure in doing things</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling down, depressed, or hopeless</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Instructions:** The questions in this scale ask you about your feelings and thoughts DURING THE LAST MONTH. In each case, please indicate how often you felt or thought a certain way.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Fairly Often</th>
<th>Very Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the last month, how often have you felt that you were unable to control the important things in your life?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In the last month, how often have you felt confident about your ability to handle your personal problems?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In the last month, how often have you felt that things were going your way?</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?</td>
<td></td>
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</tr>
</tbody>
</table>

**Instructions:** The following questions are about your health and how well you are able to do usual activities. Please answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is:

<table>
<thead>
<tr>
<th>(Choose One)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
</tr>
<tr>
<td>Very good</td>
</tr>
<tr>
<td>Good</td>
</tr>
<tr>
<td>Fair</td>
</tr>
<tr>
<td>Poor</td>
</tr>
</tbody>
</table>
The following questions are about activities you might do during a typical day. Does your health limit you in these activities? If so, how much?

2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf:

   (Choose One)
   - Yes, limited a lot [ ]
   - Yes, limited a little [ ]
   - No, not limited at all [ ]

3. Climbing several flights of stairs

   (Choose One)
   - Yes, limited a lot [ ]
   - Yes, limited a little [ ]
   - No, not limited at all [ ]

During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health:

<table>
<thead>
<tr>
<th></th>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. Accomplished less than you would like</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Were limited in the kind of work or other activities</td>
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</tbody>
</table>

6. During the past 4 weeks, how much did PAIN interfere with your normal work (including both work outside the home and housework)?

   (Choose One)
   - Not at all [ ]
   - A little bit [ ]
   - Moderately [ ]
   - Quite a bit [ ]
   - Extremely [ ]

7. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

   (Choose One)
   - All of the time [ ]
   - Most of the time [ ]
   - Some of the time [ ]
   - A little of the time [ ]
   - None of the time [ ]
**Instructions:** Please indicate how much you agree or disagree with the following statements.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Slightly Disagree</th>
<th>Neither Agree or Disagree</th>
<th>Slightly Agree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>In most ways my life is close to my ideal</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The conditions of my life are excellent</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am satisfied with life</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>So far I have gotten the important things I want in life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If I could live my life over, I would change almost nothing</td>
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<td></td>
</tr>
</tbody>
</table>

**Instructions:** Below is a list of statements dealing with your general feelings about yourself. Please indicate how much you agree or disagree with the statements.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>On the whole, I am satisfied with myself</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>At times I think I am no good at all</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel that I have a number of good qualities</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>I am able to do things as well as most other people</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel I do not have much to be proud of</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I certainly feel useless at times</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel that I am a person of worth, at least on an equal plane with others</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I wish I could have more respect for myself</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All in all, I am inclined to feel that I am a failure</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I take a positive attitude toward myself</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Instructions: Here are a number of personality traits that may or may not apply to you. Please indicate how much you agree or disagree with the statements. You should rate the extent to which the pair of traits applies to you, even if one characteristic applies more strongly than the other.

<table>
<thead>
<tr>
<th>Trait</th>
<th>Disagree strongly</th>
<th>Disagree moderately</th>
<th>Disagree a little</th>
<th>Neither agree nor disagree</th>
<th>Agree a little</th>
<th>Agree moderately</th>
<th>Agree strongly</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extraverted, enthusiastic</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Critical, quarrelsome</td>
<td></td>
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<tr>
<td>Dependable, self-disciplined</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Anxious, easily upset</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Open to new experiences, complex</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reserved, quiet</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sympathetic, warm</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disorganised, careless</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Calm, emotionally stable</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conventional, uncreative</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

Instructions: A number of statements which people have used to describe themselves are given below. Please read each statement and select the answer that best indicates how you feel right now, at this moment. There are no right or wrong answers. Do not spend too much time on any one statement, but give the answer which seems to describe your present feelings best.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not at all</th>
<th>Somewhat</th>
<th>Moderately</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel calm</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am tense</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel upset</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>I am relaxed</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel content</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am worried</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Instructions:** We are interested in how you feel about the following statements. Read each statement clearly and indicate how much you agree or disagree with each one.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Very Strongly disagree</th>
<th>Strongly disagree</th>
<th>Mildly disagree</th>
<th>Neutral</th>
<th>Mildly agree</th>
<th>Strongly agree</th>
<th>Very Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>There is a special person who is around when I am in need</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>There is a special person with whom I can share my joys and sorrows</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>My family really tries to help me</td>
<td></td>
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</tr>
<tr>
<td>I get the emotional help and support I need from my family</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have a special person who is a real source of comfort to me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My friends really try to help me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I can count on my friends when things go wrong</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I can talk about my problems with my family</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have friends with whom I can share my joys and sorrows</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>There is a special person in my life who cares about my feelings</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My family is willing to help me make decisions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I can talk about my problems with my friends</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Instructions:** Please indicate how much you agree or disagree with the statements below.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>In uncertain times, I usually expect the best</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It's easy for me to relax</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If something can go wrong for me it will</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I always look on the bright side of things</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I'm always optimistic about my future</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I enjoy my friends a lot</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It's important for me to keep busy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I hardly ever expect things to go my way</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Things never work out the way I want them to</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I don't get upset too easily</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I'm a believer in the idea that &quot;every cloud has a silver lining&quot;</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I rarely count on good things happening to me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Instructions:** Please circle a number at a point which best describes the way in which you see yourself in comparison to others. For example -

<table>
<thead>
<tr>
<th>Short</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Tall</th>
</tr>
</thead>
</table>

If you put a mark at 3 this means you see yourself as shorter than others; if you put a mark at 5 (middle) you see yourself as average; if you put a mark at 7 you see yourself as taller.

**In relationship to others I feel:**

Please choose ONE number only

<table>
<thead>
<tr>
<th>Feeling</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Superior</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inferior</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>10</td>
<td>More competent</td>
</tr>
<tr>
<td>Incompetent</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>10</td>
<td>More likeable</td>
</tr>
<tr>
<td>Unlikeable</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>10</td>
<td>Accepted</td>
</tr>
<tr>
<td>Left out</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>10</td>
<td>Same</td>
</tr>
<tr>
<td>Different</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>10</td>
<td>More talented</td>
</tr>
<tr>
<td>Untalented</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>10</td>
<td>More talented</td>
</tr>
<tr>
<td>Weaker</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>10</td>
<td>Stronger</td>
</tr>
<tr>
<td>Unconfident</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>10</td>
<td>More confident</td>
</tr>
<tr>
<td>Undesirable</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>10</td>
<td>More desirable</td>
</tr>
<tr>
<td>Unattractive</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>10</td>
<td>More attractive</td>
</tr>
<tr>
<td>An outsider</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>10</td>
<td>An insider</td>
</tr>
</tbody>
</table>
Section 2 – Your Donation

The following questions are about how you came to being a Living Kidney Donor.

1. How long ago did you first consider being a Living Kidney Donor?

   (Choose ONE answer)
   - Within the last 6 months [ ]
   - Within the last 6-12 months [ ]
   - Within the last 1-5 years [ ]
   - More than 5 years ago [ ]

2. At the time you first agreed or decided to donate, how well or unwell was your recipient?

   (Choose ONE answer)
   - Extremely unwell [ ]
   - Unwell [ ]
   - Neither well nor unwell [ ]
   - Well [ ]
   - Very well [ ]

3. Since you first agreed or decided to donate how often have you thought about it?

   (Choose ONE answer)
   - Never [ ]
   - A few times a month [ ]
   - A few times a week [ ]
   - Every day [ ]
   - I think about it constantly [ ]

4. How much do you agree or disagree with the following statement –

   “When Living Donation was first mentioned I knew instantly that I would be prepared to donate”

   (Choose ONE answer)
   - Strongly agree [ ]
   - Agree [ ]
   - Neither agree nor disagree [ ]
   - Disagree [ ]
   - Strongly disagree [ ]
5. Which of the following statements best describes your donation?

(Choose ONE answer)

I offered to donate my kidney without being asked by anyone else [ ]
I was asked to donate by the person I am donating to [ ]
I was asked to donate by someone else [ ]
(please state who ____________________________ )

6. How many other people (EXCLUDING YOURSELF) offered to donate a kidney to your recipient?

(Choose ONE answer)

There was no one else [ ]
1 [ ]
2 [ ]
3 [ ]
4 [ ]
5 or more [ ]

7. How many other people (EXCLUDING YOURSELF) went for tests AND were suitable to donate? (i.e. were a match and medically fit enough)

(Choose ONE answer)

There was no one else [ ]
1 [ ]
2 [ ]
3 [ ]
4 [ ]
5 or more [ ]

8. How long did it take for you to donate? (From initial discussion with a transplant coordinator to your operation)

(Choose ONE answer)

Within 6 months [ ]
6-12 months [ ]
12-24 months [ ]
More than 24 months [ ]
9. Since deciding to be a Living Kidney Donor, how often have you thought about:

a. **The process you will have to go through?**
   
   *(This can include any part of the donation process, including the pre-operative work up, your operation, your stay in hospital and your recovery afterwards.)*
   
   *(Choose ONE answer)*
   
<table>
<thead>
<tr>
<th>Option</th>
<th>[]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>[]</td>
</tr>
<tr>
<td>A few times a month</td>
<td>[]</td>
</tr>
<tr>
<td>A few times a week</td>
<td>[]</td>
</tr>
<tr>
<td>Every day</td>
<td>[]</td>
</tr>
<tr>
<td>I think about it constantly</td>
<td>[]</td>
</tr>
</tbody>
</table>

b. **Your social circumstances and how these may be affected by donating?**
   
   *(This can include any social issue, such as money, childcare, housing, work etc.)*
   
   *(Choose ONE answer)*
   
<table>
<thead>
<tr>
<th>Option</th>
<th>[]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>[]</td>
</tr>
<tr>
<td>A few times a month</td>
<td>[]</td>
</tr>
<tr>
<td>A few times a week</td>
<td>[]</td>
</tr>
<tr>
<td>Every day</td>
<td>[]</td>
</tr>
<tr>
<td>I think about it constantly</td>
<td>[]</td>
</tr>
</tbody>
</table>
10. In the event of concerns or doubts about going through with the operation, how easy would it be (or has it been) to discuss these with –

A. **Your recipient**

   (Choose ONE answer)
   
   - Very easy [ ]
   - Easy [ ]
   - Neither easy nor difficult [ ]
   - Difficult [ ]
   - Very difficult [ ]

B. **Your family**

   (Choose ONE answer)
   
   - Very easy [ ]
   - Easy [ ]
   - Neither easy nor difficult [ ]
   - Difficult [ ]
   - Very difficult [ ]

C. **Your friends**

   (Choose ONE answer)
   
   - Very easy [ ]
   - Easy [ ]
   - Neither easy nor difficult [ ]
   - Difficult [ ]
   - Very difficult [ ]

D. **The living donor team**

   (e.g. Your Living Donor Co-ordinator, surgeon, kidney doctor)

   (Choose ONE answer)
   
   - Very easy [ ]
   - Easy [ ]
   - Neither easy nor difficult [ ]
   - Difficult [ ]
   - Very difficult [ ]

11. How much do you agree or disagree with the following statement:

   “Of all the people involved I was the person pushing most for the Living Donor transplant to happen”

   (Choose ONE answer)
   
   - Strongly agree [ ]
   - Agree [ ]
   - Neither agree nor disagree [ ]
   - Disagree [ ]
   - Strongly disagree [ ]
12. When thinking about your RECEPIENT, how much do you worry about something going wrong or the transplant being unsuccessful?

(Choose ONE answer)

Never [ ]
A few times a month [ ]
A few times a week [ ]
Every day [ ]
I think about it constantly [ ]

Life after the transplant: These questions are about your expectations of what will happen after the Living Donor Transplant has taken place.

Please indicate how much you agree or disagree with the following statements.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree or Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>13  After the transplant my recipient’s DAY-TO-DAY life will get better</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14  After the transplant my own DAY-TO-DAY life will get better</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15  After the transplant the DAY-TO-DAY life of those around me will get better</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16  How much I benefit from my donation will depend very much on how well my recipient does</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Attitudes towards organ donation:** The following questions are about your feelings towards organ donation.

Please indicate how much you agree or disagree with the following statements.

<table>
<thead>
<tr>
<th></th>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree or Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>17</td>
<td>I think organ donation (in general) is a good thing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>I feel good about being a kidney donor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>The people closest to me support my decision to be a living donor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>Whilst I am alive I would only consider being a Living Kidney Donor to someone I know</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

21. Do you give blood?

   Yes []  No []  Not anymore []

22. Are you on the bone marrow register or have you been a bone marrow donor?

   Yes []  No []  Not anymore []  Unsure []

23. Are you on the organ donor register and/or do you hold an organ donor card? *If you have documented an intention to donate via your driving license or a store card please tick “Yes”.*

   Yes []  No []  Unsure []

24. Do you volunteer in your free time?

   Yes []  No []

25. Do you regularly give money to charity?

   Yes []  No []
Section 3 – About you
The following questions are about you. Please answer them accordingly.
If there are any questions you would prefer not to answer then please leave them blank.

1. What is your ethnic group?
   - Asian [ ]
   - Black (Afro-Caribbean) [ ]
   - Chinese [ ]
   - Mixed [ ]
   - White [ ]
   - Other [ ]
   Please state: _________________________________________

2. What religion, religious denomination or body do you belong to?
   - None [ ]
   - Protestant [ ]
   - Roman Catholic [ ]
   - Other Christian Denomination [ ]
   - Muslim [ ]
   - Buddhist [ ]
   - Sikh [ ]
   - Jewish [ ]
   - Hindu [ ]
   - Pagan [ ]
   - Another religion [ ]
   Please state: _________________________________________

2a. Please state how much you agree or disagree with the following statement –
   “My religious or spiritual beliefs were important when deciding to be a Living Kidney Donor”
   - Strongly agree [ ]
   - Agree [ ]
   - Undecided [ ]
   - Disagree [ ]
   - Strongly disagree [ ]

3. What is your highest level of education?
   (Choose ONE answer)
   - No Qualifications [ ]
   - School leaver (O-Levels, GCSEs) [ ]
   - College level (A-Levels, other college qualifications) [ ]
   - Higher Education - Any degree or professional qualification [ ]
     (For example teaching, nursing, accountancy)
   - Other [ ]

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4. Last week, were you:

(Tick all that apply)
- In employment / Training? [ ]
- Self-employed [ ]
- In education [ ]
- Retired [ ]
- Unemployed [ ]
- Other [ ]

(Please state: _________________________)

5. What is your marital or civil partnership status?

- Single [ ]
- Married / Long-term partner [ ]
- Divorced / Separated [ ]
- Widowed [ ]
- Other [ ]

(Please state: _________________________)

6. Do you have children?

Yes [ ] No [ ]

6a. If yes, how many children do you have? _____ children

7. How many children (under 18) live in your household?

______ children

8. Do you look after anyone else (excluding children) in your home?

Yes [ ] No [ ]

8a. If yes, how many people do you look after? _____ people
Living Kidney Donor Study

Post-Operative Questionnaire
Living Kidney Donors

Date of Completion: __________

Thank you for your on-going participation in our Living Kidney Donor study.

This questionnaire is made up of 3 sections:
- Section 1 – Quality of Life Questions
- Section 2 – Recovery from surgery
- Section 3 – Your Donation

Please complete each question as best as you can. If there are any questions you would prefer not to answer, please leave them blank.

Once you have completed the questionnaire please return it to the researcher.

Should you have further any questions about the study or the questionnaire then please do not hesitate to get in touch with the research team. Our contact details are provided at the end of the Patient Information Sheet.
Section 1 – Quality of Life Questions (3 and 12 months)

Instructions: Please answer the following questions on a scale of 1 to 10 (1 being the worst answer, 10 being the best).

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>How satisfied are you with your life nowadays?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>How happy did you feel yesterday?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>How anxious did you feel yesterday?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>To what extent do you feel the things you do in your life are worthwhile?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
</tr>
</tbody>
</table>

Instructions: We would like to know how you have felt about the statements below over the past few weeks. Please answer ALL the questions below by selecting the answer you think best applies to you. Remember that we want to know about present and recent health.

Have you recently...

<table>
<thead>
<tr>
<th>Question</th>
<th>Better than usual</th>
<th>Same as usual</th>
<th>Less than usual</th>
<th>Much less than usual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Been able to concentrate on whatever you’re doing?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lost much sleep due to worry?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>Felt that you are playing a useful part in things?</td>
<td>More so than usual</td>
<td>Same as usual</td>
<td>Less so than usual</td>
<td>Much less useful</td>
</tr>
<tr>
<td>Felt capable of making decisions about things?</td>
<td>More so than usual</td>
<td>Same as usual</td>
<td>Less so than usual</td>
<td>Much less capable</td>
</tr>
<tr>
<td>Felt constantly under strain?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>Felt you could not overcome your difficulties?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>Been able to enjoy your normal day-to-day activities?</td>
<td>More so than usual</td>
<td>Same as usual</td>
<td>Less so than usual</td>
<td>Much less than usual</td>
</tr>
<tr>
<td>Been able to face up to your problems?</td>
<td>More so than usual</td>
<td>Same as usual</td>
<td>Less able than usual</td>
<td>Much less able</td>
</tr>
<tr>
<td>Been feeling unhappy and depressed?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>Been losing confidence in yourself?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>Been thinking of yourself as a worthless person?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>Been feeling reasonably happy, all things considered?</td>
<td>More so than usual</td>
<td>About the same as usual</td>
<td>Less so than usual</td>
<td>Much less than usual</td>
</tr>
</tbody>
</table>
Instructions: Over the past 2 weeks, how often have you been bothered by any of the following problems?

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not at all</th>
<th>Several days</th>
<th>More than half the days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Little interest or pleasure in doing things</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling down, depressed, or hopeless</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Instructions: The questions in this scale ask you about your feelings and thoughts DURING THE LAST MONTH. In each case, please indicate how often you felt or thought a certain way.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Fairly Often</th>
<th>Very Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the last month, how often have you felt that you were unable to control the important things in your life?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In the last month, how often have you felt confident about your ability to handle your personal problems?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In the last month, how often have you felt that things were going your way?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Instructions: The following questions are about your health and how well you are able to do usual activities. Please answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

4. In general, would you say your health is:

   (Choose One)
   - Excellent [ ]
   - Very good [ ]
   - Good [ ]
   - Fair [ ]
   - Poor [ ]
The following questions are about activities you might do during a typical day. Does your health limit you in these activities? If so, how much?

5. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf:

(Choose One)
- Yes, limited a lot [ ]
- Yes, limited a little [ ]
- No, not limited at all [ ]

6. Climbing several flights of stairs

(Choose One)
- Yes, limited a lot [ ]
- Yes, limited a little [ ]
- No, not limited at all [ ]

During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health:

<table>
<thead>
<tr>
<th></th>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>Accomplished less than you would like</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>5</td>
<td>Were limited in the kind of work or other activities</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

8. During the past 4 weeks, how much did PAIN interfere with your normal work (including both work outside the home and housework)?

(Choose One)
- Not at all [ ]
- A little bit [ ]
- Moderately [ ]
- Quite a bit [ ]
- Extremely [ ]

9. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

(Choose One)
- All of the time [ ]
- Most of the time [ ]
- Some of the time [ ]
- A little of the time [ ]
- None of the time [ ]
**Instructions:** Please indicate how much you agree or disagree with the following statements.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Slightly Disagree</th>
<th>Neither Agree or Disagree</th>
<th>Slightly Agree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>In most ways my life is close to my ideal</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The conditions of my life are excellent</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am satisfied with life</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>So far I have gotten the important things I want in life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If I could live my life over, I would change almost nothing</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Instructions:** Below is a list of statements dealing with your general feelings about yourself. Please indicate how much you agree or disagree with the statements.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>On the whole, I am satisfied with myself</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>At times I think I am no good at all</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>I feel that I have a number of good qualities</td>
<td></td>
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<tr>
<td>I am able to do things as well as most other people</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel I do not have much to be proud of</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I certainly feel useless at times</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel that I am a person of worth, at least on an equal plane with others</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I wish I could have more respect for myself</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>All in all, I am inclined to feel that I am a failure</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I take a positive attitude toward myself</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Instructions:** A number of statements which people have used to describe themselves are given below. Please read each statement and select the answer that best indicates how you feel right now, at this moment. There are no right or wrong answers. Do not spend too much time on any one statement, but give the answer which seems to describe your present feelings best.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not at all</th>
<th>Somewhat</th>
<th>Moderately</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel calm</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>I am tense</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel upset</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am relaxed</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel content</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am worried</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Instructions:** We are interested in how you feel about the following statements. Read each statement clearly and indicate how much you agree or disagree with each one.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Very Strongly disagree</th>
<th>Strongly disagree</th>
<th>Mildly disagree</th>
<th>Neutral</th>
<th>Mildly agree</th>
<th>Strongly agree</th>
<th>Very Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>There is a special person who is around when I am in need</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>There is a special person with whom I can share my joys and sorrows</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>My family really tries to help me</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>I get the emotional help and support I need from my family</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>I have a special person who is a real source of comfort to me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My friends really try to help me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I can count on my friends when things go wrong</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I can talk about my problems with my family</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have friends with whom I can share my joys and sorrows</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>There is a special person in my life who cares about my feelings</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My family is willing to help me make decisions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I can talk about my problems with my friends</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Instructions:** Please indicate how much you agree or disagree with the statements below.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>In uncertain times, I usually expect the best</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It's easy for me to relax</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If something can go wrong for me it will</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I always look on the bright side of things</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I'm always optimistic about my future</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I enjoy my friends a lot</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It's important for me to keep busy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I hardly ever expect things to go my way</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Things never work out the way I want them to</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I don't get upset too easily</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I'm a believer in the idea that &quot;every cloud has a silver lining&quot;</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I rarely count on good things happening to me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Instructions:** Please circle a number at a point which best describes the way in which you see yourself in comparison to others. For example:

<table>
<thead>
<tr>
<th>Short</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Tall</th>
</tr>
</thead>
</table>

If you put a mark at 3 this means you see yourself as shorter than others; if you put a mark at 5 (middle) you see yourself as average; if you put a mark at 7 you see yourself as taller.

**In relationship to others I feel:**

Please choose ONE number only

<table>
<thead>
<tr>
<th>In comparison to others</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Superior</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inferior</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>More competent</td>
</tr>
<tr>
<td>Incompetent</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>More likeable</td>
</tr>
<tr>
<td>Unlikeable</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Accepted</td>
</tr>
<tr>
<td>Left out</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Same</td>
</tr>
<tr>
<td>Different</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>More talented</td>
</tr>
<tr>
<td>Untalented</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Stronger</td>
</tr>
<tr>
<td>Weaker</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>More confident</td>
</tr>
<tr>
<td>Unconfident</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td>More desirable</td>
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<tr>
<td>Undesirable</td>
<td></td>
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<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>More attractive</td>
</tr>
<tr>
<td>Unattractive</td>
<td></td>
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<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>An insider</td>
</tr>
<tr>
<td>An outsider</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>An insider</td>
</tr>
</tbody>
</table>

341
Section 2 - Recovery from surgery (3 months)

1. Did you have any complications once you were discharged from hospital?
   Yes [ ] No [ ]
   
   **If yes, what complication/s did you have? (please tick all that apply)**
   - Severe pain [ ]
   - Infection [ ]
     - Wound [ ]
     - Urine [ ]
     - Chest [ ]
     - Unknown source [ ]
   - Hernia [ ]
   - Other [ ] *(please state: ____________________________)*
   
   Did any of these complications require further admissions to hospital (either Guy’s or your local hospital)?
   Yes [ ] No [ ]
   
   Did any of these complications require further surgery?
   Yes [ ] No [ ]

2. Have you been prescribed **ANTIBIOTICS** by anyone after surgery? (This can be your GP, the Guy’s team or another doctor)
   Yes [ ] No [ ]
   
   **If yes, what were the antibiotics prescribed for?**
   - Wound Infection [ ]
   - Urine Infection [ ]
   - Chest Infection [ ]
   - Unknown source [ ]
   - Other Infection [ ] *(please state: ____________________________)*

3. If you are currently working, how much time did you have off before returning to work?
   I am not currently working[ ]
   Less than 4 weeks [ ]
   4-6 weeks [ ]
   6-12 weeks [ ]
   More than 12 weeks [ ]

4. If you drive, when did you return to driving after your operation?
   I do not drive [ ]
   Less than 4 weeks [ ]
   4-6 weeks [ ]
   6-12 weeks [ ]
   More than 12 weeks [ ]
5. When did you feel back to your normal self? _____ WEEKS

   I do not feel back to my normal self yet [ ]

6. Was the experience of donating (including the pre-operative workup, operation, hospital stay and recovery) –

   Much better than expected [ ]
   Better than expected [ ]
   The same as expected [ ]
   Worse than expected [ ]
   Much worse than expected [ ]

7. How much on-going pain do you have as a result of your operation? (Please score your pain out of 10)

   [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]

   No Pain  Pain as bad as it could be

Your Recipient

NB: If you participated in a paired exchange or multi-way swap please answer these questions about your friend or relative who received a kidney as part of the exchange

1. Did your recipient have any complications immediately after their surgery?

   Yes [ ]  No [ ]  Unsure [ ]

   If yes, what complications did they have? (select all that apply)
   Rejection [ ]
   Re-operation [ ]
   Severe infection [ ]
   Loss of Kidney [ ]
   Other major complication [ ]
   Other minor complication [ ]
   Other [ ]

   (please state: ________________________________)

2. Did your recipient require any dialysis after the transplant took place?

   Yes [ ]  No [ ]  Unsure [ ]
Section 2 - Recovery from surgery (12 months)

The following questions are about your recovery from surgery.

1. When did you feel back to your normal self? _____ WEEKS
   I do not feel back to my normal self yet [ ]

2. Over the past 12 months have you had any NEW medical or surgical problems related to your donor operation?
   Yes [ ]  No [ ]
   If yes, what new medical or surgical problem have you had?
   - High blood pressure [ ]
   - Urinary symptoms [ ] (please state: ____________________________)
   - Severe pain [ ] (please state LOCATION of pain: ____________________)
   - Hernia [ ]
   - Other [ ]
   (please state: ______________________________________________________
                 __________________________________________________________)

3. Over the past 12 months have you been admitted to hospital with any medical or surgical problem related to your donor operation?
   Yes [ ]  (please state: _________________________________)
   No [ ]

4. How much on-going pain do you have as a result of your operation? (Please score your pain out of 10)

   10 9 8 7 6 5 4 3 2 1 0

   No Pain  Pain as bad as it could be
Your Recipient
NB: If you participated in a paired exchange or multi-way swap please answer these questions about your friend or relative who received a kidney as part of the exchange

1. Is your recipient still alive?
   Yes [ ]   No [ ]  (If you have answered no, please go to the next page)

2. Has your recipient had any complications after their kidney transplant?
   Yes [ ]   No [ ]   Unsure [ ]
   If yes, what complications have they had? *(Please select all that apply)*
   Rejection [ ]
   Another operation (Please give details below) [ ]
   Severe infection/s requiring admission to hospital [ ]
   Other major complication [ ]
   Other minor complication [ ]
   Other [ ]
   *(please state: ______________________________________)
   ____________________________________________________________)*

3. Is the kidney still working?
   Yes [ ]   No [ ]   Unsure [ ]

4. Has your recipient required any dialysis since the transplant took place?
   Yes [ ]   No [ ]   Unsure [ ]
**Section 3 – Your Donation (3 and 12 months)**

*Life after the Transplant*: The following questions are about life after the transplant. Please indicate how much you AGREE or DISAGREE with the following statements.

*If you participated in a paired exchange or multi-way swap please answer these questions about your friend or relative who received a kidney as part of the exchange.*

*If your recipient is deceased or if you no longer see them, please select the ‘unable to comment’ box for the relevant questions.*

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree or Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
<th>Unable to comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>My recipient’s DAY-TO-DAY life is much better now than before the transplant</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My own DAY-TO-DAY life is much better now than before the transplant</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The DAY-TO-DAY lives of other people around me are better now than before the transplant</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>On the whole, my relationship with my recipient is better now than before the transplant</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>On the whole, my relationships with other people around me are better now than before the transplant</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Feelings about Donation: The following questions are about your feelings towards living donation. Please indicate how much you AGREE or DISAGREE with the following statements.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree or Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Donating a kidney is one of the best things I have ever done</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel good about being a Living Kidney Donor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If I had my time again I would not choose to be a Living Kidney Donor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have been praised for being a Living Kidney Donor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being praised for being a Living Kidney Donor is not important to me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being a Living Kidney Donor has improved my self-esteem (how I see myself)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being a Living Kidney Donor has changed my outlook on life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I will continue to feel the same way about being a Living Kidney Donor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>regardless of what happens in the future</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 5: Unspecified Donor Study (Attitudes towards donation questions)

Both groups were provided with this list of questions relating to their donation. They were provided with a Likert scale (Strongly Disagree to Strongly Agree).

Your donation: The following questions are about how you feel about your donation and what impact it has had on you.

1. I think organ donation (in general) is a good thing
2. I feel good about being a Living Kidney Donor
3. The people closest to me supported my decision to be a Living Kidney Donor
4. Donating a kidney is one of the best things I have ever done
5. If I had my time again I would not choose to be a Living Kidney Donor
6. I have been praised for being a Living Kidney Donor
7. Being praised for being a Living Kidney Donor is not important to me
8. Being a Living Kidney Donor has improved my self-esteem (how I see myself)
9. Being a Living Kidney Donor has changed my outlook on life
10. I will continue to feel the same way about being a Living Kidney Donor regardless of what happens in the future
Appendix 6: Unspecified Donor Study (Reasons for donating)

The list of reasons for wishing to donate provided to UKD sample. Participants were asked to select as many options as they wished and then to choose the most important reason for wanting to donate.

A  I wanted to help someone  
B  I wanted to do something good  
C  Donation fitted in with my morals, beliefs or my way of life (i.e. blood donation, voluntary work)  
D  I had been stopped from being a blood / bone marrow donor due to my age and wanted to donate in another way  
E  I knew someone with renal failure  
F  Someone in my own life had previously had a transplant and I therefore understood the benefits of transplantation  
G  I had previous experience of illness either affecting myself or someone I love  
H  Someone close to me died and that made me want to donate  
I  I thought donation would make little difference to my own life but a huge difference to someone else's  
J  Being a Living Donor was preferable to waiting until after I die  
K  I had religious reasons for wanting to donate  
L  I wanted to give something back to society  
M  I wanted to be admired by other people  
N  It was a way of feeling better about myself  
O  Other (Please give details)
**Appendix 7: Table 7.9**

**Table 7.9: Psychosocial outcomes in UKD and SKD groups (multiple imputation analysis)**

<table>
<thead>
<tr>
<th>Measured Outcome</th>
<th>Unspecified Kidney Donors</th>
<th>Specified Kidney Donors</th>
<th>Unadjusted mean difference</th>
<th>Adjusted mean difference*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>Mean</td>
<td>SD</td>
<td>n</td>
</tr>
<tr>
<td>Wellbeing</td>
<td>109</td>
<td>30.28</td>
<td>6.90</td>
<td>78</td>
</tr>
<tr>
<td>Life Satisfaction</td>
<td>110</td>
<td>24.67</td>
<td>7.42</td>
<td>77</td>
</tr>
<tr>
<td>Stress</td>
<td>109</td>
<td>4.03</td>
<td>3.18</td>
<td>80</td>
</tr>
<tr>
<td>Distress</td>
<td>109</td>
<td>9.99</td>
<td>4.74</td>
<td>78</td>
</tr>
<tr>
<td>Depression</td>
<td>106</td>
<td>0.66</td>
<td>1.41</td>
<td>80</td>
</tr>
<tr>
<td>Anxiety</td>
<td>107</td>
<td>10.02</td>
<td>3.86</td>
<td>77</td>
</tr>
<tr>
<td>Physical Health</td>
<td>107</td>
<td>27.86</td>
<td>4.56</td>
<td>78</td>
</tr>
<tr>
<td>Self-Esteem</td>
<td>107</td>
<td>22.11</td>
<td>5.18</td>
<td>76</td>
</tr>
<tr>
<td>Optimism</td>
<td>108</td>
<td>21.68</td>
<td>6.79</td>
<td>79</td>
</tr>
<tr>
<td>Social support</td>
<td>105</td>
<td>62.05</td>
<td>16.85</td>
<td>77</td>
</tr>
<tr>
<td>Social comparison</td>
<td>100</td>
<td>65.98</td>
<td>13.97</td>
<td>78</td>
</tr>
</tbody>
</table>

* adjusted for age at donation, sex, children, ethnicity, education
** multiply imputed estimate
Appendix 8: Thesis Publication 1: Stress predicts the trajectory of wound healing in living kidney donors as measured by high-resolution ultrasound
Stress predicts the trajectory of wound healing in living kidney donors as measured by high-resolution ultrasound

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Wound healing
Kidney donor
Transplant
Transplantation

Abstract

Background: Psychological stress has been shown to be an influential factor on the rate of wound healing; however, these findings have been demonstrated predominantly on artificially created wounds. Due to the absence of major co-morbidities, living kidney donors are a unique group in which to study this relationship. This study investigated the effect of preoperative stress and personality on surgical wound healing through the use of high-resolution ultrasound.

Methods: Living kidney donors due to undergo a hand-assisted laparoscopic donor nephrectomy were asked to complete the Perceived Stress Scale, the Life Orientation Test-Revised and the Ten Item Personality Inventory prior to surgery. High-resolution ultrasound scans of surgical wounds were performed on the first three post-operative days and once following discharge (mean = 15.3 days; s.d. 2.8). Two measurements from each image were obtained: wound width (size of wound) and median intensity (a marker of tissue fluid). Latent Growth Curve Models (LGCMs) were used to evaluate wound healing.

Results: 52 living kidney donors participated. Higher pre-operative life stress, lower optimism and lower conscientiousness were associated with delayed wound healing in living kidney donors for both outcomes. Increased emotional stability was associated with faster wound healing as demonstrated by a change in median intensity. Possible confounding factors, such as age, BMI, smoking status, local anaesthetic use and wound drain placement were not influential.

Conclusions: This study, which measured wound healing in a novel patient sample using a novel technique, has demonstrated a negative association between stress and wound healing and the positive influence of optimism, conscientiousness and emotional stability.

1. Introduction

Psychological stress has been shown to be an influential factor on the rate of wound healing in different parts of the body, in different clinical circumstances and through the use of different modalities (Gouin and Kiecolt-Glaser, 2011). A wound is defined as a disruption of normal anatomical structure and function (Lazarus et al., 1994) and healing of any wound necessitates a step-wise process in which a variety of different inflammatory mediators are involved to facilitate repair to the damaged area. The wound healing process is dependent on a broad range of internal and external factors, one of which is a fully functional immune system that is able to respond appropriately to tissue injury (Walburn et al., 2009). It is through the immunological pathway that stress is thought to have a modulatory influence (Segerstrom and Miller, 2004) via activation of the hypothalamic-pituitary-adrenal axis and the sympathetic-adrenal-medullary axis. It is also recognised that stress can have significant behavioural effects, for example on diet (Torres and Nowson, 2007) and sleep (Ohayon, 2009), which, in turn, affect the speed of wound healing.

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\textit{Abbreviations:} AIC, Akaike information criteria; BIC, Bayesian information criteria; BMI, Body Mass Index; CFI, Comparative Fit Index; CRP, C-reactive protein; eGFR, estimated Glomerular Filtration Rate; LGCM, Latent Growth Curve Model; LOT, Life Orientation Test; LOT-R, Life Orientation Test-Revised; MLR, Maximum Likelihood estimator; RMSEA, Root Mean Square Error of the Approximation; TLI, Tucker Lewis Index; WW, wound width.

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0889-1591/© 2014 Elsevier Inc. All rights reserved.
Although the link between psychological stress and healing is well established, there are few studies that have evaluated cutaneous surgical wounds (Holden-Lund, 1988; Scheier et al., 1999; Broadbent et al., 2003, 2012; Doering et al., 2005). These studies have demonstrated that increased psychological stress is associated with an increase in wound complications, such as infection (Doering et al., 2005; Scheier et al., 1999), and reduced levels of inflammatory markers, such as interleukin-1 (IL-1) and metalloproteinase-9 (MMP-9) (Broadbent et al., 2003). Randomised studies of psychological intervention to minimise stress in surgical patients have demonstrated an improvement in wound healing in the intervention group (Holden-Lund, 1988; Broadbent et al., 2012).

Living kidney donors are a unique group of patients in which to examine the association between stress and surgical wound healing for two reasons. Firstly, they are patients who, prior to surgery, are extensively screened for both physical and psychological pathologies and are only allowed to donate if fit. They should therefore be free from all major physical and psychological comorbidities that may directly affect wound healing. Secondly, they are healthy but undergo major surgery for the benefit of another individual, with no physical benefits to themselves. It is therefore crucial that they recover quickly from the procedure with few complications in order to minimise the physical trauma of surgery. The risk of death from living kidney donation is currently quoted as 3 in 10,000 donations (Segev et al., 2010) and the rate of any morbidity (defined as “the incidence of at least any one complication per donor”) is 10.3% for laparoscopic living donor nephrectomy and 15.7% for open surgery (Hadjianastassiou et al., 2007). The rate of wound infection for donors undergoing hand-assisted laparoscopic donor nephrectomy is 2.2% (Matas et al., 2003, Pareek et al., 2006).

The evaluation of potential living kidney donors is carried out according to an evidence-based protocol which involves a series of appointments and investigations. A full assessment is undertaken by a nephrologist and a transplant surgeon who elicit a detailed medical and surgical history from the donor. The aim of this is to determine whether there are any potential contraindications to donation. A detailed physical examination is performed to assess for potentially undiagnosed pathologies and also to permit planning for surgery. A number of medical tests are routinely performed including urinalysis, blood tests, vireology and infection screens, cardiac investigations (i.e. electrocardiography) and radiological examinations, such as a chest X-ray. A detailed assessment of kidney function is also performed and includes radiological tests, such as an ultrasound and either a computerised tomography scan (CT scan) or an angiogram.

Guidelines regarding the psychological assessment of living donors are less prescribed and a formal evaluation of the donor’s psychological state is not mandated. Referral to psychological services is recommended when requested by the patient or when an issue is detected as part of the workup process. The relative psychological contraindications to living kidney donation are previous or current mental health illness, active substance abuse, dependence on prescribed medication, self-harming behaviour or significantly dysfunctional family relationships, particularly between recipient and donor. Over a thousand living donor procedures take place across the UK each year (NHS Blood and Transplant, 2013). The process of donating a kidney is often very stressful for a donor, not just because of their own operation but because a loved one is frequently undergoing an operation on the same day. To date, no evaluation has been made as to whether there are any modifiable factors that may predict recovery from surgery in these patients.

In addition to stress, personality has also been shown to impact upon health outcomes, both directly through physiological mechanisms and indirectly through patient behaviour. Conscientiousness is thought to lead to a healthier, longer life through the collective reduction of many small risks, which result from conscientious behaviour. Further, highly conscientious individuals report fewer daily stresses (O’Connor et al., 2009) and engage in more adaptive coping styles (Grant and Langan-Fox, 2006; Kern and Friedman, 2008), suggesting that personality may moderate the potentially damaging effects of stress, which has been referred to as the stress moderation model (Weibe et al., 2010). Lower levels of optimism have been associated with slower wound healing (Ebrecht et al., 2004) and an increase in wound infection and all-cause rehospitalisation after coronary artery bypass graft surgery (Scheier et al., 1999). Combinations of personality traits have also been demonstrated as being particularly harmful, such as a low level of conscientiousness coupled with high neuroticism, which leaves an individual at high risk of poor health outcomes (Friedman and Kern, 2014).

The aim of this study was to evaluate the trajectory of wound healing in living kidney donors using high-resolution ultrasound, and to ascertain what potentially modifiable factors predict recovery. High resolution ultrasound (HRUS) was the chosen modality to assess wound healing because it provides an objective, reliable, non-invasive method of quantitatively assessing structural changes deep within a wound that correlates highly with tissue histology, photography and nuclear magnetic resonance spectroscopy (Dyson et al., 2003; Harland et al., 1993; Hu et al., 1998; Rippon et al., 1998). The HRUS machine provides a detailed image of the different layers of the skin, through which the size of the wound and differences in the fluid content can be measured. HRUS has been used on one previous occasion to investigate the association between wound healing and stress (Ebrecht et al., 2004) and although the use of HRUS to measure skin tissue fluid content has not previously been used in psychological research, it has been extensively validated in other studies (Gniadecka et al., 1994, 1995; Seidenari and Di Nardo, 1992a,b).

Specifically we tested the following hypothesis: pre-operative life stress will predict the trajectory of wound healing. Given the prediction of the stress-moderation model, we also explored whether optimism and the ‘Big Five’ personality factors were predictive of wound healing, and tested if interactions between stress and personality predicted the rate of wound healing.

2. Materials and methods

2.1. Design

This study was conducted between August 2012 and May 2013 and used a prospective observational design. Patients completed questionnaires between 1 and 2 weeks preoperatively. Wounds were evaluated during hospital admission (days 1, 2 and 3) and at follow up, approximately 2–3 weeks after surgery.

2.2. Sample

A consecutive sample of living kidney donors from a single centre donating over a six month period were recruited (n = 58). The sample included adult donors principally from the south east of England but also from across the United Kingdom (UK) and overseas. Exclusion criteria included anyone who was unable to speak or read English without the use of an interpreter. Donors were approached by a researcher on one occasion two to four weeks prior to scheduled surgery, following completion of all medical tests and appointments. Formal written consent was obtained. NHS research ethics approval for the study was obtained (09-H0804-31).
2.3. Materials

Donors were asked to complete the following questionnaires prior to surgery:

2.3.1. Perceived Stress Scale (PSS) (Cohen et al., 1983)

The 4-item version of the PSS was used to measure the degree to which situations in one's life over the preceding month are viewed as stressful. Answers are based on a five-point scale: 0 = never, 1 = almost never, 2 = sometimes, 3 = fairly often, 4 = very often. Scores are obtained by summing up all four items. Scoring of items 2 and 3 are reverse coded. Total scores range from 0–20 with higher scores indicating more perceived stress.

2.3.2. The Big Five personality inventory (Gosling et al., 2003)

This scale provides a brief assessment of “The Big Five” personality dimensions. It includes ten items, two for each of the personality traits extraversion, agreeableness, conscientiousness, openness and emotional stability. Participants are provided with a pair of analogous personality characteristics and asked to select an answer based on how much they identify with them. Answers are based on a seven-point scale: 1 = Disagree strongly, 2 = Disagree moderately, 3 = Disagree a little, 4 = Neither agree nor disagree, 5 = Agree a little, 6 = Agree moderately, 7 = Agree strongly. Five items, one for each personality trait, are reverse coded. A sum score for each personality trait was calculated from both questions, with higher scores indicating that the individual identifies more with that particular personality trait.

2.3.3. Life Orientation Test-Revised (LOT-R) (Scheier et al., 1994)

This 10-item version of the Life Orientation Test (LOT) was used to measure optimism, or more specifically, a person’s expectations regarding the favourability of future outcomes. Answers are based on a five-point scale: 0 = strongly disagree, 1 = disagree, 2 = neutral, 3 = agree and 4 = strongly agree. Four of the items are fillers and are not used in scoring. A final score is obtained by summing up the remaining 6 items, of which 3 are reverse scored (items 3, 7 and 9). Total scores range from 0–24 with higher scores indicating higher optimism.

2.4. Surgical and hospital procedure

Donors were admitted to hospital on the day of surgery and underwent their procedure on an elective operating list by a consultant transplant surgeon. The centre uses a hand-assisted laparoscopic technique, which is a modified form of keyhole surgery. The patient is left with three wounds after their operation (Fig. 1). The largest is the ‘hand-port’ which is a vertical or horizontal wound located in the midline of the abdomen, either above or below the umbilicus. This provides access for the surgeon’s hand during the operation and is the extraction site for the kidney. This wound is 7–10 cm in length and is the largest of the three. Two smaller wounds (5–10 mm) are used for the laparoscopic instrument and the camera. For continuity, all donors received the same skin closure and the same dressing. In order to facilitate wound scanning, surgical glue was applied as an alternative to an opaque adhesive dressing. A subcutaneous wound drain (which sits in the fatty layer just beneath the skin) was inserted into the hand-port wound at the surgeon’s discretion.

Donors were visited by the research team on the first three post-operative days whilst they were in hospital (day 1 being the day after surgery). Visits were made in the mornings at the same time each day to ensure 24 h had passed between scans. The hand-port wound was scanned during each research visit. Following discharge donors were seen in the outpatient clinic 10–20 days after their operation, at which point the same wound was scanned for the final time. All scans for each subject were conducted by the same researcher (HM, SS or VL) to reduce inconsistency in scanning techniques. Routine blood tests including full blood count, renal and liver profile and C-reactive protein (CRP) were collected at baseline and at follow up.

2.5. Image capture

All wounds were scanned using the Episcan® high-resolution ultrasound machine and a hand-held 20 MHz probe. To obtain an image the abdomen was exposed and ultrasound gel placed on the wound, on top of the glue dressing. This ensured that the wound was not directly exposed to the ultrasound probe, thereby minimising the risk of infection. The probe was placed on top of the ultrasound gel, pressed gently onto the wound and moved until a cross-sectional image was displayed on the screen. The image was then captured and the process repeated until the researcher was confident that at least one good quality image had been obtained. The final position of scanning on the wound was documented to ensure consistency with the scans performed on subsequent days. The same area was scanned in the same manner at all four time points by the same individual.

2.6. Image analysis

For each donor, the best quality image at each time point was selected (four images from days 1–3 and follow-up). The wound area is easily identifiable on the image as an area of black (a reflection of its increased fluid content) located immediately beneath a break in the normal structure of the tissue (Fig. 2).

The first 3 millimetres (mm) beneath the epidermis was used for analysis as this was the most consistent area of skin between patients and was the part least affected by Body Mass Index (BMI). Image analysis started with the images taken on day 1. A 3 mm line was dropped from beneath the epidermis in the centre of the wound. A “wound area” box was then drawn around it to represent the wound area (Fig. 3). The width of the wound (WW) was measured as the width of the box and an additional measurement (median intensity (MI)) was also taken (Fig. 4). MI is a reading produced by the Episcan® imaging software and reflects the fluid content in the defined area. Injured tissue has a higher fluid content due to the occurrence of post-operative oedema (swelling). Oedema is caused by the body’s natural reaction to surgery whereby the area in and around the surgical wound is infiltrated with tissue fluid. Higher fluid content is reflected by a lower MI score reading, which will subsequently increase as the tissue heals and the fluid is absorbed. The advantage of using MI is that it quantifies the change in oedema over time, which is not always visible to the naked eye.

Fig. 1. Possible wound sites for hand-assisted laparoscopic donor nephrectomy.
Once both WW and MI measurements had been taken for the day 1 image, the box was copied onto the centre of the image selected for day 2. WW was calculated by drawing a horizontal line over the widest part of the wound, which may have been greater or less than the width of the wound on day 1. Median intensity was similarly calculated using the same box area so a comparison could be made between days 1 and 2. This process was repeated for day 3 and for the follow up images. The total number of readings per donor was 8: 1 wound width and 1 median intensity measurement for each time point.

2.7. Reliability

The images were analysed independently by two researchers (HM, SS or VL) on separate days. This was to increase validity and avoid researcher bias. Additional steps to reduce bias included anonymising the data and blinding the researchers to the questionnaire scores. Inter-rater reliability was examined to ensure that the wound assessment method was effective. A correlation for measurements taken at the individual time points showed that all were correlated highly (r > 0.8, p < 0.05), thereby demonstrating consistency between both researchers. For the main statistical analysis, the averages (mean) in wound measurements from both sets of data were used.

2.8. Statistical analysis

Latent Growth Curve Models (LGCMs) were used to evaluate wound healing over approximately 2 weeks. All models were run in Mplus version 7.11 using the Robust Maximum Likelihood estimator (MLR). The models were run using the TSCORES option in Mplus, since the time in which donors were scanned at the final follow-up (time 4) varied between 10-20 days (average follow-up = 15.3 [s.d] = 2.8). This particular kind of growth model uses the actual time of the follow-up (days 1, 2 and 3 were fixed accordingly; the actual time of the final follow-up was included in the model). Unconditional univariate LGCMs for both MI and WW were first evaluated. Linear and non-linear models were evaluated (data not shown). For both MI and WW, linear change models were the most appropriate, showing good model fit based upon Akaike (AIC) and Bayesian information criteria (BIC). Since MI measures tissue oedema, a conditional LGCM was then examined, which controlled for whether a post-operative wound drain was inserted (dummy coded variable). Further conditional LGCMs for both MI
and WW were ran in order to evaluate the effect of stress and personality on wound healing. This was achieved by regressing the intercept and slope of the respective wound healing models (MI and WW), onto the predictor variables (stress, personality and stress-personality interactions). Interactions were modelled using centred means.

Since the growth models used TSCORES, convention model fit criteria (e.g. the Comparative Fit Index [CFI], Tucker Lewis Index [TLI], The Root Mean Square Error of the Approximation [RMSEA]) cannot be computed. However linear growth models examining the trajectory of both MI and WW across days 1–3 post surgery (i.e. three fixed time points) demonstrated good fit according to these standard indices (CFI >0.92; RMSEA <0.08).

3. Results

3.1. Sample characteristics

A consecutive sample of fifty-eight donors consented to and participated in the study. 6 were excluded from the analysis due to prolonged follow up time necessitated for clinical reasons. This left 52 patients for analysis. The average time between patients completing the preoperative questionnaires and the day of the donation was 12.2 days (s.d. = 5.6). Demographic and clinical details are provided in Table 1. Forty-three donors (82.7%) had no medical or psychiatric issues requiring medication at the time of donation. Nine donors were medicated for one or more of the following medical problems: hypertension, hypothyroidism, hyperthyroidism, asthma, hypercholesterolaemia and gastrooesophageal reflux disease. Six donors (11.5%) had a previous history of a mental health condition, including depression (5 donors) and Post-Traumatic Stress Disorder (PTSD) (1 donor). Eight donors (15.4%) had an active mental health condition including depression requiring medications (4 donors), anxiety disorder (1 donor), mixed anxiety and depression (2 donors) and stress (1 donor). The mean stress and optimism scores were 4.78 (s.d. 2.6) and 20.2 (6.5), respectively. Mean scores on The Big Five personality domains were as follows: extraversion 9.1 (s.d. 3.2), agreeableness 10.0 (s.d. 2.3), conscientiousness 11.3 (s.d. 2.4), openness 10.3 (s.d. 2.4) and emotional stability 9.8 (s.d. 2.96). As expected, patients’ preoperative bloods were unremarkable. The most common type of donation was parent to child (n = 21, 40.3%). Local anaesthetic was used in 33 donors (63.5%) and a wound drain inserted into 11 (21.1%). The average length of stay was 4 days (minimum = 2 days; maximum = 7 days) and the average time between discharge and follow up was 15.3 days; [s.d.] = 2.8).

3.2. Image characteristics

The mean wound width and median intensity scores are provided in Table 2. As expected, the wound width decreases and the median intensity score increases over time, which reflects the wound healing process. The median intensity value was obtained by copying the same box area used on the other images for that donor.

Unsuitability of the hand-port wound for scanning accounted for missing data (day 1 = 2%, day 2 = 6%, day 3 = 8%, follow-up = 8%). Wounds were not scanned when the dressing had leaked, where there was a break in the skin, or evidence of infection (erythema and swelling of the wound) since this would increase the risk of introducing further infection and would limit the quality of image obtained.

3.3. Correlates of preoperative stress at baseline

Preoperative life stress was unrelated to age, gender, smoking status, preoperative serum haemoglobin, serum albumin, estimated Glomerular Filtration Rate (eGFR), C-reactive protein, Body Mass Index and length of hospital stay (effect sizes between 0.01 to 0.20, p values >0.05). In addition preoperative stress was not associated with the number of days between completing the stress measure and date of the surgery (r = −0.13, p = 0.40). Mean stress scores were significantly higher in individuals donating to a child compared to a friend or other relative (mean difference = 1.6, [95% CI 0.26 and 3.1], p = 0.02). Stress scores correlated significantly and negatively with optimism (r = −.57, p < 0.01) conscientiousness (r = −.36, p = 0.01) and emotional stability (r = −.53, p < 0.01), but were unrelated to extraversion, openness to experience and agreeableness.

3.4. LGCM: trajectory of wound healing as measured by wound median intensity

A LGCM for MI was run (AIC = 791.1; BIC = 808.4; number of free parameters = 9). Specifically, both the intercept and slope was significant (Table 3), although the variance in the change over time (slope [days]) was non-significant. The mean change in the slope was .22 (p < 0.01), indicating that per unit of time, MI was increasing significantly by 0.22 units. Since the longitudinal evaluation of MI could be influenced by the insertion of a wound drain, a conditional growth model was evaluated which controlled for wound drain use (dummy coded variable correlated with both the intercept and the slope). This conditional growth model had slightly better fit than the unconditional model, evidence by a

| Table 1 | Demographic and clinical data (n = 52). |

<table>
<thead>
<tr>
<th>Variable</th>
<th>Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>29 (55.8%)</td>
</tr>
<tr>
<td>Female</td>
<td>23 (44.2%)</td>
</tr>
<tr>
<td>Mean age at donation (years, SD)</td>
<td>45.5 (12.9)</td>
</tr>
<tr>
<td>Donor-recipient relationship</td>
<td></td>
</tr>
<tr>
<td>Parent to child (&lt;18)</td>
<td>10 (19.2%)</td>
</tr>
<tr>
<td>Parent to child (&gt;18)</td>
<td>11 (21.2%)</td>
</tr>
<tr>
<td>Spouses</td>
<td>10 (19.2%)</td>
</tr>
<tr>
<td>Siblings</td>
<td>5 (9.6%)</td>
</tr>
<tr>
<td>Child to parent</td>
<td>3 (5.8%)</td>
</tr>
<tr>
<td>Distant relatives</td>
<td>5 (9.6%)</td>
</tr>
<tr>
<td>Friends</td>
<td>4 (7.7%)</td>
</tr>
<tr>
<td>Altruistic donor</td>
<td>4 (7.7%)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>47 (90.4%)</td>
</tr>
<tr>
<td>Non-white</td>
<td>5 (9.6%)</td>
</tr>
<tr>
<td>Smoking status</td>
<td></td>
</tr>
<tr>
<td>Current smoker</td>
<td>5 (9.6%)</td>
</tr>
<tr>
<td>Non-smoker</td>
<td>47 (80.4%)</td>
</tr>
<tr>
<td>BMI (mean, SD)</td>
<td>26.2 (3.6)</td>
</tr>
<tr>
<td>Pre-operative blood results (mean, SD)</td>
<td></td>
</tr>
<tr>
<td>Haemoglobin (g/dL)</td>
<td>16.2 (15.4)</td>
</tr>
<tr>
<td>Male</td>
<td>14.9 (14.9)</td>
</tr>
<tr>
<td>Female</td>
<td>13.2 (13.2)</td>
</tr>
<tr>
<td>Albumin (g/L)</td>
<td>46.1 (2.1)</td>
</tr>
<tr>
<td>Creatinine (μmol/L)</td>
<td>79.1 (14.0)</td>
</tr>
<tr>
<td>eGFR (mL/min)</td>
<td>83.8 (14.1)</td>
</tr>
<tr>
<td>CRP (mg/L)</td>
<td></td>
</tr>
<tr>
<td>&lt;5 (not inflamed)</td>
<td>49 (94.2%)</td>
</tr>
<tr>
<td>&gt;5 (inflamed)</td>
<td>3 (5.8%)</td>
</tr>
</tbody>
</table>

| Table 2 | Image data for each time point (Mean and S.D.). |

<table>
<thead>
<tr>
<th>Variable</th>
<th>Day 1</th>
<th>Day 2</th>
<th>Day 3</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>n</td>
<td>49</td>
<td>47</td>
<td>47</td>
<td>47</td>
</tr>
<tr>
<td>Wound width (mm)</td>
<td>6.92 (1.98)</td>
<td>6.12 (1.84)</td>
<td>5.85 (1.78)</td>
<td>4.90 (1.99)</td>
</tr>
<tr>
<td>Median intensity</td>
<td>6.71 (1.83)</td>
<td>7.35 (2.03)</td>
<td>7.42 (2.05)</td>
<td>10.15 (3.76)</td>
</tr>
</tbody>
</table>
reduction in both the AIC and BIC (AIC = 727.3; BIC = 747.7; number of free parameters = 11) so was used in subsequent analysis. Both mean intercept and slope factors were significant (Table 3). Wound drain was significantly associated with the intercept mean (beta = 1.7, p < 0.01) but not with the slope.

3.5. LGCM: trajectory of wound healing as measured by wound width

A LGCM model for wound width showed similar findings to the MI models, with comparable model fit (AIC = 719.1; BIC = 736.3; number of free parameters = 9). Both the intercept and slope factors were significant (Table 3). Per unit of time, wound width was reducing by 0.10 units (mm).

3.6. Predictors of the rate of wound healing

A summary of stress and personality factors as predictors of the intercept and slope (change) for both MI and WW are shown in Table 4. Stress significantly predicted the rate of wound healing for both MI and WW. A point increase in stress at baseline was associated with a −0.03 decrease in the change of MI per unit of time (p < 0.01) and 0.02 increase in WW per unit of time (p < 0.01). Conscientiousness and optimism also significantly predicted the slopes in both MI and WW models (Table 4), suggesting that higher levels of both constructs are associated with quicker rates of wound healing. Emotional stability was associated with the change in MI (beta = 0.02, p < 0.01), but not WW (beta = −0.07, p = 0.09).

3.7. Exploring the interaction of stress and personality upon wound healing

Since stress, optimism and conscientiousness predicted the change (i.e. the slope) of wound healing as measured by MI and WW, the interaction between personality and stress was tested in subsequent LGCMs. Two models were evaluated testing the interaction between stress and conscientiousness and stress and optimism (using centred means). In both models, the interaction term (stress * personality/optimism) was specified to predict the intercept and the slope factors for both MI and WW. For both measures of wound healing, the stress * personality/optimism (conscientious or optimism) was not associated with the rate of wound healing (p > 0.05). Conscientiousness however, remained a significant predictor of the change (slope) for both MI and WW (MI; beta = 0.02; WW beta = −0.17, p < 0.05), although the effect of stress in both models became non-significant.

4. Discussion

To our knowledge, this is the first study to examine the relation between psychological factors and wound healing in living kidney donors. Our findings demonstrate that increased psychological stress is associated with delayed wound healing in living kidney donors across two separate markers: wound width (size) and median intensity (level of tissue oedema/swelling), supporting our primary hypothesis. Furthermore, it was found that optimism and conscientiousness predicted wound healing as measured by both wound width and median intensity, and increased emotional stability was associated with faster wound healing, as demonstrated by a change in median intensity. Possible confounding factors, such as age, BMI, smoking status, the use of local anaesthetic and placement of a subcutaneous wound drain were not found to be influential. The main strengths of this study lie in the use of a genuine surgical wound with which to assess wound healing, the use of two separate ultrasonographic markers, one of which (median intensity) has not previously been used in this field, and the unique patient sample. With regards to the later, unlike other surgical wound healing studies, our patients were free from significant physical or psychological co-morbidities since they were healthy donors. Accordingly, the potential of confounding due to variation in underlying health issues is minimal, and thus provided a novel surgical group to examine wound healing.

The association between increased stress and delayed wound healing is not a new phenomenon with other studies demonstrating an association using a variety of different techniques, both in animal and human experiments (Kiecolt-Glaser et al., 1995; Marucha et al., 1998; Padgett et al., 1998). High-resolution ultrasound is a relatively novel way to assess cutaneous wound healing (Dyson et al., 2003) and has been used on one previous occasion to investigate the association between wound healing, stress, and optimism (Ebrecht et al., 2004). It has also been used in the assessment of renal transplant patients, but this was with the primary aim of detecting evidence of rejection within the transplant kidney rather than an assessment of the wound itself (Calvin et al., 1997).

By demonstrating a slower reduction in wound width in those patients with increased stress, this study has replicated the findings demonstrated by Ebrecht et al. (2004). In addition, this study has provided further supportive evidence in the form of an additional ultrasonographic marker of wound healing (median intensity), which has not previously been used in psychological research. The use of an ultrasonographic method to assess wound healing is beneficial as not only does it provide
quantitative data with which to make an objective assessment of the wound, it also provides information about what is taking place beneath the skin. The latter point is especially useful in surgical wounds where the epidermis is closed with a suture and a dressing applied. The additional advantage of using a median intensity reading is that it allows detection of very subtle differences within the skin which are invisible to the naked eye. The use of two independent raters with high inter-rater reliability in this study provides additional strength to the findings.

Living kidney donors are a unique group of patients on which to assess the impact of stress on wound healing as they are free from major underlying physical and psychological pathology yet they undergo major surgery. They therefore have genuine surgical wounds on which to assess wound healing without any of the potential confounding factors that may be present in an alternative surgical patient sample undergoing an operation for their own benefit, for example cancer, infection or an inflammatory process. In addition, living kidney donation is often an incredibly stressful procedure as the donor is usually undergoing surgery on the same day as a loved one. An advantage of demonstrating that psychological stress as an influential factor for wound healing is that it is a modifiable factor, which may be reduced by a pre-operative psychological intervention.

There have been a number of randomised studies that have demonstrated improved wound healing after a psychological intervention, both in surgical patients and healthy individuals (Holden-Lund, 1988; Broadbent et al., 2012; Weinman et al., 2008; Koschwanez et al., 2013). Techniques have included Relaxation with Guided Imagery (RGI) (Holden-Lund, 1988; Broadbent et al., 2012) and an emotional disclosure intervention (expressive writing) (Weinman et al., 2008; Koschwanez et al., 2013). In these studies wounds have been assessed by photography, the presence of hydroxyproline within the wound (as a measure of collagen deposition) and subjective wound assessment by the Wound Assessment Inventory (WAI). Both of these interventions, which are brief and easy to administer, may provide a cost-effective way of reducing pre-operative psychological stress in this patient sample. This is especially important in this group of patients, as they are undergoing surgery for the benefit of another person and the harm inflicted by surgery ought to be kept as minimal as possible.

The effect of personality on surgical recovery is also not a new phenomenon; however the impact of personality on rates of wound healing is relatively novel. In the Ebrecht study (2004), in addition to higher stress, lower trait optimism was also found to be associated with inferior rates of wound healing. In our study lower optimism, conscientiousness and emotional stability were associated with inferior wound healing, however there was no interaction between any of these factors and stress, as would be predicted from the stress-moderation model. It is possible that reduced conscientiousness may be associated with poorer adherence to post-operative advice regarding wound care, ambulation and physical activity, and it is through this behavioural mechanism that the effect on wound healing takes effect. Donors are advised to keep their wounds protected through the use of topical dressings and to assess them for evidence of infection or inflammation at each dressing change. If evidence of infection is present they are advised to attend the hospital for a surgical review. Donors are additionally advised to ambulate slowly and to abstain from heavy lifting for 3 months. Emotionally stable patients may heal quicker for similar reasons, and additionally may have more social support, which can be helpful during the recovery process.

Limitations of this study include the variable time to follow up (10–20 days) and the measurement of stress at a single pre-operative time point. The level of donor stress may have been related to the underlying health of the recipient, and may have increased due to pain or unforeseen post-operative incidents; data which we did not collect. Additional markers of stress, such as cortisol, would also have provided additional supportive evidence to the ultrasonographic findings, as well as potentially providing a further explanation behind the results. Future studies should measure stress on more than one occasion, possibly the day before surgery and at least once during the post-operative recovery period, and include high resolution ultrasonography alongside biochemical markers, such as cortisol or inflammatory cytokines, within serum or drain fluid samples (Kiecolt-Glaser et al., 1995; Marucha et al., 1998; Glaser et al., 1999; Broadbent et al., 2003; Ebrecht et al., 2004). Further considerations regard the present studies sample size, which limited the power of the growth models to detect interactions between stress and personality. Larger studies would allow model reliable evaluations of the interactions examined here. In relation to other potential predictive factors of wound healing, other cognitive, behavioural and social factors not examined here should be considered as these may also point to future targets for intervention.

5. Conclusions

This study, measuring wound healing in a novel patient sample using a novel technique, has demonstrated a negative association between stress and wound healing and the positive influence of optimism, conscientiousness and emotional stability. Future wound healing research using high-resolution ultrasound should utilise the median intensity measurement to provide additional data that is not visible to the naked eye.

Acknowledgments

This research was funded by the Guy’s and St Thomas’ Charity and was supported by the National Institute for Health Research (NIHR) Biomedical Research Centre at Guy’s and St Thomas’ NHS Foundation Trust and King’s College London. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

References


Appendix 9: Thesis Publication 2: Motivations, outcomes, and characteristics of unspecified (non-directed altruistic) kidney donors in the United Kingdom
Motivations, Outcomes, and Characteristics of Unspecified (Nondirected Altruistic) Kidney Donors in the United Kingdom

Hannah Maple, Joseph Chilcot, Lisa Burnapp, Paul Gibbs, Alastair Santhouse, Sam Norton, John Weinman, and Nizam Mamode

Background. Unspecified (nondirected altruistic) kidney donation is becoming increasingly common in the United Kingdom. Questions regarding motivation and characteristics of these donors persist, alongside concerns about regret and long-term psychosocial outcomes. The aims of this study were to compare psychosocial and physical outcomes in unspecified kidney donors (UKDs) versus specified kidney donors (SKDs).

Methods. We performed a cross-sectional study, in which a detailed assessment of psychosocial outcomes was made using validated questionnaires. Additional questions specific to donation were also asked, including questions regarding motivation, regret, and anonymity.

Results. One hundred ninety responses were received from 296 participants studied (110 UKDs [74.3%] vs. 80 SKDs [45.1%], P=0.001). Unspecified kidney donors were older (54 years vs. 44 years; P<0.001), predominantly white (99.1% vs. 78.5%; P<0.001), and donated more recently (1.3 years vs. 2.6 years; P<0.001). There was no difference in psychiatric history or personality type, or current depression, anxiety, stress, self-esteem, or well-being between the groups (P>0.05). Unspecified kidney donors were more engaged in other altruistic behaviours (P=0.001). There was no difference in physical outcomes, although UKDs recovered quicker (P=0.001). Regret was low (3.7% UKDs vs. 7.5% SKDs; P=0.078).

Conclusion. This study has demonstrated that UKDs have comparable physical and psychosocial outcomes to SKDs. These favorable outcomes may be, in part, because of the rigorous evaluation process which currently includes a mental health assessment. We conclude that the program can continue to expand safely across the United Kingdom.

Keywords: Living donor, Kidney transplantation, Altruistic kidney donation, Unspecified kidney donation.

Living kidney donation now accounts for more than one in three of all kidney transplants performed in the United Kingdom. The donation of a kidney from a living person to a stranger (someone with whom they have no genetic or emotional relationship) was legalized in 2006 and has led to more than 200 donations across the United Kingdom.

Many different terms have been used for these donors including altruistic, anonymous, nondirected, “Good Samaritan,” and unspecified. The Ethical, Legal, and Psychosocial Aspects of Transplantation section of the European Society for Organ Transplantation has agreed on the term “unspecified kidney donation” (UKD) (1), and we use that nomenclature here.

Unspecified kidney donation is growing in popularity (Fig. 1), and after an initial slow start by some, most U.K.

H.M. participated in research design, performance of the research, data analysis and writing of the article. J.C. participated in research design, data analysis, and writing of the article. L.B. participated in research design and writing of the article. P.G. participated in research design and editing of the article. A.S. participated in research design and editing of the article. S.N. participated in data analysis and writing of the article. J.W. participated in research design and editing of the article. N.M. participated in research design and writing and editing of the article.

Supplemental digital content (SDC) is available for this article. Direct URL citations appear in the printed text, and links to the digital files are provided in the HTML text of this article on the journal’s Web site (www.transplantjournal.com).

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There was a significant difference between the groups in the number of responses received (110 UKDs [74.3%] vs. 80 SKDs [54.1%]; \( P<0.001 \)). Table 1 displays the demographic data for both groups. The UKD group were on average 10 years older and predominantly of white ethnicity, were less likely to be currently working (33.9% retired), have children, or have current dependents. The UKD group showed a higher incidence of previous surgery and, despite no difference in mental health history, showed more commonly experienced episodes of low mood lasting more than 2 weeks. Geographical data were limited but demonstrated that only a small number of UKDs donated away from their nearest transplant center (7 vs. 80 donors; \( P<0.001 \)). In the SKD group, there was no significant difference in sex between responders and nonresponders; however, nonresponders were found to be significantly younger (38.2 years vs. 44.0 years; \( P=0.001 \)). Sex and age data were not available for nonresponders in the UKD group.

Motivations and Donor Characteristics

Most UKDs were made aware of altruistic kidney donation through the media (64 donors [58.2%]) or through researching other forms of donation (10 donors [9.1%]). Other modes included knowing someone with renal failure or a transplant (12.8%) and knowing someone who had been a living kidney donor (UKDs or SKDs) (5.5%). A minority were made aware by family, friends, or a religious organization (3.6%), had heard about UKD through work (5.5%), or considered the idea of their own accord (2.7%). The most common reasons for donating were “I thought my donation would make little difference to my own life but a huge difference to someone else’s” (30 UKDs [27.3%]) and “I wanted to help someone” (13 UKDs [11.8%]) (Table S1, SDC, http://links.lww.com/TP/B33).

There was no significant difference in personality traits between the two groups across each of the personality domains measured (extraversion \( [P=0.586] \), agreeableness \( [P=0.719] \), conscientiousness \( [P=0.719] \), emotional stability \( [P=0.418] \), and openness \( [P=0.948] \)). No personality trait was identified as being more common in either group. The UKDs were found to be more altruistic in other areas when compared with SKDs across five separate markers of altruism:

![FIGURE 1. Total number of unspecified kidney donations taking place per year in the United Kingdom (data to 31st December 2013).](image)

**Demographics**

One hundred ninety responses were received from the 296 questionnaires distributed (64.2% total response rate).

There was a significant difference between the groups in the number of responses received (110 UKDs [74.3%] vs. 80 SKDs [54.1%]; \( P<0.001 \)). Table 1 displays the demographic data for both groups. The UKD group were on average 10 years older and predominantly of white ethnicity, were less likely to be currently working (33.9% retired), have children, or have current dependents. The UKD group showed a higher incidence of previous surgery and, despite no difference in mental health history, showed more commonly experienced episodes of low mood lasting more than 2 weeks. Geographical data were limited but demonstrated that only a small number of UKDs donated away from their nearest transplant center (7 vs. 80 donors; \( P<0.001 \)). In the SKD group, there was no significant difference in sex between responders and nonresponders; however, nonresponders were found to be significantly younger (38.2 years vs. 44.0 years; \( P=0.001 \)). Sex and age data were not available for nonresponders in the UKD group.

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![FIGURE 2. Range in the number of unspecified kidney donations performed in total per U.K. transplant center (data to 31st December 2013).](image)
### TABLE 1. Demographic details

<table>
<thead>
<tr>
<th>Category</th>
<th>UKD (%)</th>
<th>SKD (%)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>59 (53.6)</td>
<td>38 (47.5)</td>
<td>0.403</td>
</tr>
<tr>
<td>Female</td>
<td>51 (46.4)</td>
<td>42 (52.5)</td>
<td></td>
</tr>
<tr>
<td><strong>Mean age at donation</strong></td>
<td></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Range</td>
<td>19–83</td>
<td>20–69</td>
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<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>White</td>
<td>108 (99.1)</td>
<td>62 (78.5)</td>
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<tr>
<td>Non-white</td>
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<td>0.12</td>
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<td>60 (54.5)</td>
<td>52 (65.8)</td>
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<td>50 (45.5)</td>
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<td>Higher education</td>
<td>64 (58.7)</td>
<td>39 (51.3)</td>
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<tr>
<td>Other/no education</td>
<td>45 (41.3)</td>
<td>37 (48.7)</td>
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<tr>
<td><strong>Employment status</strong></td>
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<tr>
<td>Currently working</td>
<td>68 (62.4)</td>
<td>67 (83.8)</td>
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<tr>
<td>Retired</td>
<td>37 (33.9)</td>
<td>8 (10)</td>
<td></td>
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<tr>
<td>Unemployed</td>
<td>4 (3.7)</td>
<td>5 (6.2)</td>
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<tr>
<td><strong>Relationship status</strong></td>
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<td>0.012</td>
</tr>
<tr>
<td>Married/long-term partner or widowed</td>
<td>69 (62.7)</td>
<td>63 (79.7)</td>
<td></td>
</tr>
<tr>
<td>Single or divorced/separated</td>
<td>41 (37.3)</td>
<td>16 (20.3)</td>
<td></td>
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<tr>
<td><strong>Children</strong></td>
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<td>0.036</td>
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<td>Yes</td>
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<td>59 (73.8)</td>
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<tr>
<td>No</td>
<td>45 (40.9)</td>
<td>21 (26.2)</td>
<td></td>
</tr>
<tr>
<td><strong>Current dependents</strong></td>
<td></td>
<td></td>
<td>0.028</td>
</tr>
<tr>
<td>&lt;18</td>
<td>7 (6.4)</td>
<td>13 (16.2)</td>
<td></td>
</tr>
<tr>
<td>&gt;18</td>
<td>6 (5.5)</td>
<td>12 (15)</td>
<td></td>
</tr>
<tr>
<td><strong>Medical history</strong></td>
<td></td>
<td></td>
<td>0.166</td>
</tr>
<tr>
<td>Yes</td>
<td>27 (24.5)</td>
<td>13 (16.2)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>83 (75.5)</td>
<td>67 (83.8)</td>
<td></td>
</tr>
<tr>
<td><strong>Previous surgical history</strong></td>
<td></td>
<td></td>
<td>0.004</td>
</tr>
<tr>
<td>Yes</td>
<td>66 (60)</td>
<td>31 (38.8)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>44 (40)</td>
<td>49 (61.3)</td>
<td></td>
</tr>
<tr>
<td><strong>Previous mental health history</strong></td>
<td></td>
<td></td>
<td>0.134</td>
</tr>
<tr>
<td>Yes</td>
<td>31 (28.2)</td>
<td>15 (18.8)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>79 (71.8)</td>
<td>65 (81.2)</td>
<td></td>
</tr>
<tr>
<td><strong>Formal mental health diagnosis received</strong></td>
<td></td>
<td></td>
<td>0.950</td>
</tr>
<tr>
<td>Yes</td>
<td>8 (25.8)</td>
<td>4 (26.7)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>23 (74.2)</td>
<td>11 (73.3)</td>
<td></td>
</tr>
<tr>
<td><strong>Mental health treatment received</strong></td>
<td></td>
<td></td>
<td>0.524</td>
</tr>
<tr>
<td>Yes</td>
<td>27 (87.1)</td>
<td>14 (93.3)</td>
<td></td>
</tr>
<tr>
<td>Medication</td>
<td>12 (44.4)</td>
<td>7 (50.0)</td>
<td></td>
</tr>
<tr>
<td>Therapeutic intervention</td>
<td>10 (37.0)</td>
<td>4 (28.6)</td>
<td></td>
</tr>
<tr>
<td>Medication and therapeutic interventions</td>
<td>5 (18.5)</td>
<td>3 (21.4)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>4 (12.9)</td>
<td>1 (6.7)</td>
<td></td>
</tr>
<tr>
<td><strong>Episodes of low mood lasting &gt; 2 weeks</strong></td>
<td></td>
<td></td>
<td>0.019</td>
</tr>
<tr>
<td>Yes</td>
<td>63 (57.3)</td>
<td>48 (60)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>47 (42.7)</td>
<td>32 (40)</td>
<td></td>
</tr>
</tbody>
</table>

*Percentages calculated of those with a previous mental health history.
Statistically significant.
UKD, unspecified kidney donors; SKD, specified kidney donors.
blood donation (77.3% vs. 45.0%; \(P<0.001\)), bone marrow registration (30.3% vs. 7.5%; \(P=0.001\)), organ donor registration (94.5% vs. 58.8%; \(P<0.001\)), participation in volunteer work (56.4% vs. 32.5%; \(P=0.001\)), and monetary donations to charity (82.7% vs. 65.0%; \(P=0.005\)).

**Postoperative Psychosocial Outcomes**

The UKD group donated more recently (1.3 years vs. 2.6 years; \(P=0.001\)) which reflects the increase in numbers of people becoming UKDs in the past 12 months. Table 2 contains both unadjusted and adjusted difference scores for each of the psychosocial measures used. Adjusted models controlled for age at donation, time since donation, sex, relationship status, children, ethnicity, education, employment status, and previous low mood lasting more than 2 weeks. Across the psychological measures used, no significant difference was demonstrated between the two groups. A significant difference was demonstrated in the perceived level of social support and social comparison (i.e., where one sees oneself in relation to others), but this difference became insignificant in the adjusted model.

**Physical Outcomes**

Due to many donors donating less than 12 months before the study, limited 12-month and 24-month clinical follow-up data were available. Objective physical outcome measures, such as blood pressure, estimated glomerular filtration rate, serum creatinine, and hemoglobin were not found to be statistically different between the groups when controlling for age, sex, and preoperative values. There was no significant difference in the rate of complications or the number of complications requiring further admissions to hospital (11 UKDs vs. 8 SKDs; \(P=0.956\)) or reoperation (3 UKDs vs. 6 SKDs; \(P=0.121\)). There was no significant difference in length of stay (UKDs 3.65 days vs. SKDs 3.95 days \(P>0.05\)). When comparing responders and nonresponders in the UKD sample, there was no difference in postoperative outcomes (blood results, blood pressure, rate of complications, and length of stay). Subjective markers of recovery demonstrated faster recovery in the UKD group, such as return to work (4–6 weeks vs. 6–12 weeks; \(P<0.001\)), return to driving (<4 weeks vs. 6–12 weeks; \(P=0.001\)), and return to feeling normal (6 weeks vs. 12 weeks; \(P=0.001\)). There was no significant difference in residual operative site pain (\(P=0.156\)) (Table 3).

**Regret and Attitudes**

The donation-specific questions (Table S2, SDC, http://links.lww.com/TP/B33) demonstrated that both groups equally felt that organ donation in general was a good thing (109 UKDs [99.1%] vs. 80 SKDs [100%]) and that they felt

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**TABLE 2.** Psychosocial outcomes in UKD and SKD groups

<table>
<thead>
<tr>
<th>Measured outcome</th>
<th>UKDs n</th>
<th>Mean SD</th>
<th>SKDs n</th>
<th>Mean SD</th>
<th>Unadjusted difference</th>
<th>SE</th>
<th>(P)</th>
<th>Adjusted difference (^a)</th>
<th>SE</th>
<th>(P)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wellbeing (Office of National Statistics Wellbeing questions)</td>
<td>109</td>
<td>30.28</td>
<td>6.90</td>
<td>78</td>
<td>30.86</td>
<td>6.14</td>
<td></td>
<td>-0.57</td>
<td>0.98</td>
<td>0.558</td>
</tr>
<tr>
<td>Life satisfaction (satisfaction with life scale)</td>
<td>110</td>
<td>24.67</td>
<td>7.42</td>
<td>77</td>
<td>25.13</td>
<td>6.99</td>
<td></td>
<td>-0.46</td>
<td>1.08</td>
<td>0.672</td>
</tr>
<tr>
<td>Stress (4-item perceived stress scale)</td>
<td>109</td>
<td>4.03</td>
<td>3.18</td>
<td>80</td>
<td>4.65</td>
<td>2.99</td>
<td></td>
<td>-0.62</td>
<td>0.46</td>
<td>0.174</td>
</tr>
<tr>
<td>Distress (General Health Questionnaire 12)</td>
<td>109</td>
<td>9.99</td>
<td>4.74</td>
<td>78</td>
<td>10.22</td>
<td>4.30</td>
<td></td>
<td>-0.23</td>
<td>0.68</td>
<td>0.737</td>
</tr>
<tr>
<td>Depression (Patient Health Questionnaire 2)</td>
<td>106</td>
<td>0.66</td>
<td>1.41</td>
<td>80</td>
<td>0.69</td>
<td>1.11</td>
<td></td>
<td>-0.03</td>
<td>0.19</td>
<td>0.887</td>
</tr>
<tr>
<td>Anxiety (State-Trait Anxiety Inventory)</td>
<td>107</td>
<td>10.02</td>
<td>3.86</td>
<td>77</td>
<td>10.60</td>
<td>4.35</td>
<td></td>
<td>-0.58</td>
<td>0.61</td>
<td>0.343</td>
</tr>
<tr>
<td>Physical health-related quality of life (short form-12: physical components only)</td>
<td>107</td>
<td>27.86</td>
<td>4.56</td>
<td>78</td>
<td>28.01</td>
<td>3.18</td>
<td></td>
<td>-0.15</td>
<td>0.60</td>
<td>0.799</td>
</tr>
<tr>
<td>Self-esteem (Rosenberg)</td>
<td>107</td>
<td>22.11</td>
<td>5.18</td>
<td>76</td>
<td>23.18</td>
<td>5.33</td>
<td></td>
<td>-1.07</td>
<td>0.79</td>
<td>0.175</td>
</tr>
<tr>
<td>Optimism (Life Orientation Test—Revised)</td>
<td>108</td>
<td>21.68</td>
<td>6.79</td>
<td>79</td>
<td>20.89</td>
<td>5.98</td>
<td></td>
<td>0.79</td>
<td>0.96</td>
<td>0.410</td>
</tr>
<tr>
<td>Social support (Multidimensional Scale of Perceived Social Support)</td>
<td>105</td>
<td>62.05</td>
<td>16.85</td>
<td>77</td>
<td>67.60</td>
<td>14.13</td>
<td></td>
<td>-5.55</td>
<td>2.36</td>
<td>0.020b</td>
</tr>
<tr>
<td>Social comparison (Social Comparison Scale)</td>
<td>100</td>
<td>65.98</td>
<td>13.97</td>
<td>78</td>
<td>71.38</td>
<td>13.72</td>
<td></td>
<td>-5.40</td>
<td>2.09</td>
<td>0.011b</td>
</tr>
</tbody>
</table>

\(^a\) Adjusted for age at donation, time since donation, sex, relationship status, children, ethnicity, education, employment status, previous low mood lasting more than 2 weeks.

\(^b\) Statistically significant.

UKD, unspecified kidney donors; SKD, specified kidney donors; SD, standard deviation; SE, standard error of the mean.
good about being a living kidney donor (106 UKDs (96.7%) vs. 76 SKDs (95%)). Neither group felt that donating had increased their self-esteem. The SKD group had received more praise (P=0.02), had higher perceived social support for their decision to donate (P<0.001), and considered their donation as a more significant life event (P=0.002). Current regret was low for both groups (4 UKDs vs. 6 SKDs; P=0.078), and there was no difference when anticipating regret in the future (6 UKD vs. 10 SKD; P=0.052).

**DISCUSSION**

This study is the largest study of unspecified donors that has ever been conducted, both in its sample size and the range of psychosocial outcome measures used. It is the only study that compares those who have donated a kidney entirely anonymously to a stranger with those who have donated a kidney to a loved one. It is also the only study that has attempted to capture data from a consecutive, nationwide sample of UKDs where every individual who has donated was invited to participate. The main findings of this study are that there is no significant difference in personality, psychosocial, or physical outcomes or regret between UKDs and SKDs. UKDs recover more quickly from surgery, are motivated by a desire to help others, and are more likely to engage in other forms of altruistic behavior. Communication from the recipient is welcomed; however, very few UKDs desire formal contact.

There is a broad literature related to UKD but very little clinical data. Most articles outline different UKD guidelines and practices (6–9); provide commentaries on donation, altruism, and the role of the psychiatrist (10–14); present the views of transplant physicians (15); and consider the role of UKDs in initiating living donor chains (16, 17). The ethical aspects and practicalities of UKD have also been discussed at length (18–20). Few clinical studies have been performed, all with sample sizes of less than 50 UKDs (21–28), and only one has used a comparison group of SKDs (28).

This study has demonstrated equivalent levels of stress, anxiety, distress, and depression between the two groups. This demonstrates that there is no negative psychological impact after UKD when compared to SKD. Similarly, levels of wellbeing, life satisfaction, self-esteem, and optimism were also equivalent. This demonstrates that there is no significant difference in how UKDs feel about their quality of life and toward themselves. As discussed previously, the body of evidence in support of UKD is limited. The five small studies that precede our work have suggested that both physical and psychosocial outcomes may be acceptable and comparable with SKDs, although it is impossible to draw definitive conclusions because of the small number of donors assessed and the small range of measures used.

The only study with a similar design to ours is the study by Rodrigue et al. (28). This study also demonstrated no difference between SKDs and a mixed sample of UKDs (which included those donating completely anonymously, as in our sample, and those donating to a named individual; so-called directed altruistic donation); however, the sample size of purely anonymous UKDs was small (19 donors), and only two validated questionnaires were used. Our study is able to provide the transplant community with the most convincing evidence to date that UKDs and SKDs have equivalent psychological outcomes after donation. All UKDs in this sample would have received a mental health assessment before donation, and although it is not possible to know how those who were screened out would have fared had they been allowed to donate, we can be reassured that those who have been allowed

### TABLE 3. Physical outcome measures

<table>
<thead>
<tr>
<th>Physical outcome variable</th>
<th>UKDs</th>
<th>SKDs</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Serum creatinine (umol/L)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12 months</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Systolic blood pressure (mmHg)</td>
<td>48</td>
<td>48</td>
<td>0.719</td>
</tr>
<tr>
<td>Diastolic blood pressure (mmHg)</td>
<td>48</td>
<td>48</td>
<td>0.634</td>
</tr>
<tr>
<td>eGFR (mL/min)</td>
<td>53</td>
<td>67</td>
<td>0.055</td>
</tr>
<tr>
<td>Serum creatinine (umol/L)</td>
<td>53</td>
<td>67</td>
<td>0.226</td>
</tr>
<tr>
<td>Hemoglobin (g/dL)</td>
<td>50</td>
<td>67</td>
<td>0.413</td>
</tr>
<tr>
<td>24 months</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Systolic blood pressure (mmHg)</td>
<td>25</td>
<td>36</td>
<td>0.203</td>
</tr>
<tr>
<td>Diastolic blood pressure (mmHg)</td>
<td>25</td>
<td>36</td>
<td>0.863</td>
</tr>
<tr>
<td>eGFR (mL/min)</td>
<td>29</td>
<td>54</td>
<td>0.634</td>
</tr>
<tr>
<td>Serum creatinine (umol/L)</td>
<td>29</td>
<td>54</td>
<td>0.719</td>
</tr>
<tr>
<td>Hemoglobin (g/dL)</td>
<td>23</td>
<td>53</td>
<td>0.872</td>
</tr>
</tbody>
</table>

Adjusted for age, sex, and preoperative values.
eGFR, estimated glomerular filtration rate; UKD, unspecified kidney donors; SKD, specified kidney donors; SD, standard deviation.

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**Note:**

The ethical considerations of this study were approved by the University of Birmingham Ethics Committee (registration number 10–583).
to donate do well postoperatively. What is perhaps more surprising is why the SKD group did not have superior results to the UKD group, as one may hypothesize that there should be an additional psychological benefit to SKDs from seeing their recipient well and further benefit from improvements in their own lives as a secondary positive outcome.

The UKD group showed a higher incidence of previous surgery, which may be accounted for by the increased age. Despite being 10 years older, the UKD group recovered significantly quicker across all markers of subjective recovery. This may provide additional insight into how highly motivated these donors are toward their operation and subsequent recovery or may reflect additional physical demands placed on recovering SKDs who may provide care for their recipient.

This study is limited by its retrospective design and regional SKD comparison group. The clinical history and outcomes were mostly self-reported and may be subject to bias. There may be some selection bias within the sample with fewer responses from those with negative experiences or those with poor psychosocial outcomes. In addition, it was also not possible to establish where (i.e., which transplant center) the UKDs nonresponders were from and their reasons for not wishing to participate. A further limitation is the size of the SKD comparison group which resulted in low statistical power to detect adverse outcomes, such as regret. A nationwide prospective study is needed to further evaluate some of these issues and should allow for a more in-depth analysis of the impact of donation by comparing preoperative and postoperative scores. Finally, this study investigated the largest cohort of available UKDs at the time, which encompassed the first 5 years in the history of the U.K. UKD programme. The speed with which the programme has expanded has moved UKD from exceptional to usual practice and promotion by patient groups. The findings of this study are inevitably influenced by the change in approach to UKDs by the clinical community.

When looking to the future, UKD is becoming more popular in the United Kingdom. Completion of a mandatory mental health assessment has been removed by the Human Tissue Authority but currently remains the agreed clinical standard. This study has demonstrated that a mental health history does not prohibit UKD nor does it increase the likelihood of an adverse postoperative outcome. Our sample of UKDs would have all undergone a mental health assessment, some of whom may have found it to be the most concerning part of their workup (29). There are no data available regarding the sensitivity and specificity of these assessments or whether they can be safely removed, yet there are still large numbers of potential UKDs who are screened out for a variety of psychosocial reasons (30). Given the positive psychosocial outcomes reported from this study and the reliance on positive outcomes to further expand the programme, it may be prudent for mental health assessments to remain best practice until further evidence is available.

This article has demonstrated that UKDs have comparable physical and psychosocial outcomes to SKDs. There is little regret and very little contact between donors and recipients. These findings are encouraging and support continued and safe expansion of the U.K. programme with the expectation of favorable outcomes.

MATERIALS AND METHODS

Sample

We performed a cross-sectional evaluation of psychosocial outcomes in a national sample of UKDs. This included all 148 UKDs who had donated in the United Kingdom since the scheme began in February 2007 until the study ended in November 2012. The UKDs were recruited through lists obtained from NHSBT. The UKD sample was compared with 148 SKDs recruited from Guy’s Hospital. Every SKD undergoing surgery at Guy’s Hospital between 2007 and July 2012 was considered for inclusion. Those SKDs who had not been followed up at Guy’s Hospital and those involved in other psychology research studies (40 patients involved in a prospective quantitative study running simultaneously) were excluded. A list of 298 donors remained which was then sorted by date of donation. Alternate names were then selected.

All donors were sent a questionnaire by post and were provided with an option to complete it on paper or online by means of a secure website. One postal reminder was sent after four weeks. The questionnaire consisted of three sections:

Section 1

Demographic questions (ethnicity, religious beliefs, highest level of education, current employment and relationship status, number of children, and number of dependents in their household). The UKD sample received additional purposely designed questions relating to their donation (including timing and location, awareness of the programme, and motivations). A list of reasons for donating was provided (Table S1, SDC, http://links.lww.com/TP/B33), and UKDs were asked to select which reasons were applicable before selecting a single most important reason.

Section 2

Twelve validated questionnaires investigating a range of psychosocial factors (Table 4). Validated abbreviated versions of questionnaires were used where possible to decrease responder burden.

Section 3

Donation-specific questions. These were divided into medical history (including surgical procedures and mental health), alternative markers of altruism (including blood donation, bone marrow and organ donor registration, regular charitable donations and volunteer work), and postoperative recovery (complications, residual pain and return to driving, work and normal function). Both groups were asked ten questions about their feelings toward their donation (Table S2, SDC, http://links.lww.com/TP/B33) and were provided with a five-point Likert scale (strongly disagree to strongly agree). The UKD group were asked additional questions related to recipient contact.

All new questions were tested for face and content validity on a separate sample of 20 SKDs and modified accordingly before being retested and finalized.

A retrospective evaluation of clinical outcomes at 12 and 24 months was also performed. Physical outcome data for all UKDs (including nonresponders) was cross-linked securely from NHSBT by the national organ donor number (blood pressure, estimated glomerular filtration rate, serum creatinine, and hemoglobin). An analysis of responders vs. nonresponders was performed focussing on length of stay, major complications, and the year of donation to determine whether those who had not responded experienced inferior physical outcomes. Physical outcome data for the SKD group was obtained from hospital records. Self-reported data were cross-checked with objective clinical data where possible.

National Health Service research ethics approval was obtained (09-H0804-31).

Statistical Analysis

Comparisons between UKD and SKD groups were evaluated using chi-square (Fisher’s exact test), Student’s t test, and analysis of variance models.
TABLE 4. Validated questionnaires

<table>
<thead>
<tr>
<th>Measured outcome</th>
<th>Rating scale used</th>
<th>No. of items, range of scores</th>
<th>Score interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Well-being</td>
<td>Office of National Statistics Wellbeing questions (32)</td>
<td></td>
<td>4 items; range, 0–40</td>
</tr>
<tr>
<td>Life satisfaction</td>
<td>Satisfaction with life scale (33)</td>
<td></td>
<td>Higher scores indicate higher levels of well-being</td>
</tr>
<tr>
<td>Stress</td>
<td>4 item Perceived stress scale (34)</td>
<td></td>
<td>5 items; range, 5–35</td>
</tr>
<tr>
<td>Distress</td>
<td>General Health Questionnaire 12 (35)</td>
<td></td>
<td>Higher scores indicate higher life satisfaction</td>
</tr>
<tr>
<td>Depression</td>
<td>Patient Health Questionnaire 2 (36)</td>
<td></td>
<td>4 items; range, 0–16</td>
</tr>
<tr>
<td>Anxiety</td>
<td>State-trait anxiety inventory (37)</td>
<td></td>
<td>Higher scores indicate more stress</td>
</tr>
<tr>
<td>Physical health-related quality of life</td>
<td>Short form 12 (physical components only) (38)</td>
<td></td>
<td>12 items; range, 0–36</td>
</tr>
<tr>
<td>Self-esteem</td>
<td>Rosenberg self-esteem scale (39)</td>
<td></td>
<td>Higher scores indicate greater distress</td>
</tr>
<tr>
<td>Optimism</td>
<td>Life orientation test—revised (40)</td>
<td></td>
<td>2 items; range, 0–6</td>
</tr>
<tr>
<td>Social support</td>
<td>Multidimensional scale of perceived social support (41)</td>
<td></td>
<td>Higher scores indicate greater depressive symptoms</td>
</tr>
<tr>
<td>Social comparison</td>
<td>Social comparison scale (42)</td>
<td></td>
<td>6 items; range, 6–24</td>
</tr>
<tr>
<td>Personality</td>
<td>10 item personality inventory (43)</td>
<td></td>
<td>Higher scores indicate more anxiety</td>
</tr>
</tbody>
</table>

as appropriate. Unadjusted and adjusted mean differences between the donor groups for the psychological variables were calculated using multivariable linear regression analysis. To control for potential confounding effects, adjustment controlled for age at donation, time since donation, sex, relationship status, number of children, ethnicity (white vs. non-white), education (higher education vs. less than higher education), employment status, and previous low mood lasting more than 2 weeks. Both unadjusted and adjusted mean difference scores (standard errors) are presented. P values less than 0.05 were considered as significant. Presence of missing data for the variables in the analysis was low, ranging between 0 and 12 observations per variable (0% and 6.3%). Because the spread of missing data across variables meant omitting between 10 (5.3%) and 21 (11.1%) observations in the complete case analysis to calculate adjusted mean group differences, a multiple imputation analysis was conducted where missing data were imputed across 10 data sets using the chained equations approach (31). The results from the multiple imputation analysis are provided in the supporting information (Table S3, SDC, http://links.lww.com/TP/B33). Because the proportion of missing data for individual variables was low, sensitivity analysis for a nonignorable missingness was not necessary. Statistical analysis was performed using SPSS (version 20; IBM, Armonk, NY) and Stata (version 12.1; StataCorp, College Station, TX).

ACKNOWLEDGMENTS
The authors thank Patricia Swetman from Guy’s and St Thomas’ National Health Service Trust and the statistics and data services teams at NHSBT for their administrative support.

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